

Making Best Interests Decisions:

People and Processes

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Appendices available as PDF documents from all the following websites:

www.bristol.ac.uk/norahfry

www.mentalhealth.org.uk

www.applied-social-research.brad.ac.uk

- A BIDS analytical report 1: The online survey**
- B BIDS analytical report 2: The telephone survey**
- C BIDS analytical report 3: Interviews**
- D Appendix on people with dementia**
- E Appendix on DOLS**
- F Focus group report**

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Val Williams, Marcus Jepson, Pauline Heslop (Bristol); Geraldine Boyle (Bradford); Toby Williamson and Paul Swift (Mental Health Foundation).

Executive Summary

This research study was about professional practices in best interests decision making under the Mental Capacity Act (MCA), and was carried out in 2010-11, in four contrasting areas of England, amongst health, social care and legal professionals. The data were drawn from:

- 1) Online survey (N= 385 responses).
- 2) Telephone interviews (N= 68)
- 3) Interviews (25 cases, with multiple or single interviews).

When and why are best interests decisions made?

- A wide range of best interests decisions was covered in the research. Serious deterioration in health was the most common trigger, often leading to a consideration of other matters, such as personal welfare or risk. **(2.1)**
- Discharge from hospital and change of accommodation was the second largest context for making a best interests decision. **(2.2)**
- About one in five best interests decisions were made for more than one reason; although this is contrary to MCA guidance, participants related this to the complexity of the situation for some people lacking capacity. **(2.2)**
- Risk was a very common trigger for a best interests process, and best interests decisions were taken to protect people from harm. **(2.3)**
- Concerns about financial capacity, or about possible financial abuse, also led to best interests decisions in a few cases in this research. The research suffered however from under-recruitment of corporate deputies and legal professionals. **(2.3)**
- A specific change in social care needs could also give rise to a best interests decision. For instance, that accounted for 35 of the 93 social care cases in the online survey. **(2.4)**

- Everyday or routine best interests decisions were under-represented in the early stages of this research, although they were deliberately followed up in later stages. It would seem that not all care home staff, for instance, are currently confident about their duties under the MCA. **(2.4)**

Assessment of capacity

- In accordance with the MCA, 70% (271) of the best interests processes in the online survey were preceded by an assessment that someone lacked capacity. However, it was worrying that one in ten best interests decisions did not follow an assessment that the person lacked capacity. **(3.1 & 3.4)**
- Determining whether or not someone had capacity, even for a specific decision, was considered the most difficult aspect of the Act.**(3.4)** Despite this, there was good practice reported in giving good support, prompts, and repeated chances to ‘regain’ capacity with some groups of people **(3.3 and 10.2.1)**
- Joint assessments of capacity were common. 18 out of 68 cases in the telephone survey involved more than one assessor. **(3.1)**
- Assessments of capacity were most likely to happen on the same day as the best interests decision (49% of those in the online survey). However, that pattern varied slightly for different groups of people; for instance, people with learning disabilities were more likely to have had a capacity assessment a week or more before the decision process. **(3.2)**
- There were several blurred aspects to the notion of capacity. For instance, the ability to manage for oneself (executorial capacity) was often confused with the ability to decide for oneself, and strong personalities were often said to sway capacity assessment. Unwise decisions were very hard to disentangle from an assessment that someone lacked capacity, especially when the assessment was made on the basis of lack of understanding of one’s own needs for protection or care. A lack of capacity was commonly equated with a lack of insight into one’s own changing health care needs or condition. **(3.3 & 3.4)**

- Capacity assessments and best interests decisions were often described as overlapping processes. We described this as the ‘concertina effect’. **(3.2)**
- The MCA instructs practitioners that there should always be a presumption of capacity, unless proved otherwise. However, this principle was not always adhered to. About one quarter of best interests decisions were made on the basis of a capacity assessment relating to history, diagnosis or disability, age, appearance or behaviour, or the fact that someone was making an unwise decision. This seemed to indicate a reasonably widespread lack of understanding of the MCA **(3.3)**

The process of best interests decision making

- Most participants in this research favoured joint or consensus decision making, over being a sole decision maker. People were often reluctant to take on the responsibility for best interests decisions on their own. However, clarity and coordination were essential, and we had examples of cases in which the process had failed because of lack of a decision maker. **(4.2)**
- There was a distinction between leading a best interests process and actually being the decision maker. On occasions, these two functions were carried out by different people. **(4.2)**
- Formal structures brought in by the MCA were not highly represented in this research. That includes the ability to make a lasting power of attorney (LPA), to have a corporate deputy involved, or to use an advance directive. However, where they were used or discussed in relation to particular cases, they were very helpful in clarifying matters. **(4.3)**
- Urgent decisions that had to be made in under 24 hours were more often associated with health care than with other matters. Urgent situations, for instance, those including paramedics, were successful if there was a person who was clearly taking responsibility, who was well informed about the MCA.. Disagreements however led to longer processes, and delays could be either beneficial or problematic. **(4.1 & 5.5)**

- Over half of all decisions involved a series of meetings between the decision-maker, the person and usually others who knew the person. However health care decisions were significantly more likely than other types of decisions to be made at a single meeting, or at meeting(s) that did not involve the person lacking capacity. All these meetings worked best if there had been good preparation and consultation beforehand. **(4.4)**
- Those in multi-disciplinary teams often held regular meetings, where best interests decisions were incorporated as part of the standing agenda. Best interests were also considered in some cases as part of other processes, such as safeguarding. **(4.4.3)**
- A special best interests meeting for a patient or client could take many different shapes. In some cases, an 'executive' meeting fed into a larger more formal meeting; at other times a single best interests meeting pulled together relevant parties, and the outcome was then fed into a regular multi-disciplinary process. **(4.4.4)**
- Health or social care staff making a best interests decision that results in someone's liberty being restricted must seek authorisation through the Deprivation of Liberty safeguards (DOLS). Over a third of the decisions in the research potentially required such authorisation, yet some workers were unaware of the safeguards. **(4.4.5)**
- Best interests decisions were not always made via meetings; sometimes they were made through informal processes, such as conversations around a bedside. Informal processes were also relevant in everyday decisions in care homes. However, it was then even more important to find a way to record matters well, and person-centred plans were said to be useful in determining in general how best interests decisions may be made. **(4.4.6)**
- Successful decision making processes were undertaken when the decision maker or leader was clear about stating the parameters of the decision to be made, and when the person lacking capacity had already been prepared or consulted outside the meeting. We noted that often one 'major' best interests decision often led to a raft of sub-decisions. **(4.5)**

Involving the person lacking capacity and those close to him/her

- 47% of people lacking capacity were involved in best interests meetings with multiple participants. People with learning disabilities were significantly less likely to be invited to a formal meeting, and those with dementia were more likely. However, meetings were not the only, nor necessarily the best, way to involve people lacking capacity. **(5.1)**
- Communication with a person lacking capacity was sometimes more successfully accomplished outside meetings, and with accessible information strategies or real-life experiences, or observation. We explored examples where trust was built up over a period of time. **(5.2 & 5.3)**
- Although most people said they had taken into account the wishes and values of the person lacking capacity, there were only a few clear examples where wishes and values were influential in the best interests decision, or where past values had been explored. **(5.3)**
- 88% of respondents in the online survey felt that people close to the person lacking capacity had been consulted, and 86% felt that their views had been taken into account. Their views could be very influential in the final decision; in several cases, family members effectively dictated what should happen **(5.4)**
- In some cases, disagreements had arisen with family members or friends. In others, mistrust of a family member had given rise to the best interests process. In some cases therefore, the process of involvement was geared towards persuading or influencing the family member's view. However, where there were suspicions of abuse, family members were excluded from the best interests process and informed afterwards about the outcome. **(5.5)**

IMCAs

- Where an IMCA was instructed, they were generally involved in best interests meetings, and four of the seven who filled in the online survey said they were involved in making the decision. **(6.1)**

- IMCAs were sometimes appointed when there was a conflict with family members or suspicion about their motives. Their commitment to the person lacking capacity, however, sometimes reinforced disputes. **(6.2 and 6.3)**
- There was a greater proportion of disagreement in cases involving IMCAs. While it is hard to tell why that is, IMCAs said that they would challenge bad practice under the MCA, which could have led to constructive criticism from IMCAs. **(6.4)**
- Although there is a general lack of awareness of the finer aspects of the IMCA role **(6.5)**, nevertheless both IMCAs and professionals leading best interests decisions agreed that swiftness in appointment of an IMCA is important. **(6.6)**

Recording of best interests decisions and assessment of capacity

- Most best interests processes were recorded formally, with about one third of the online respondents using formal note-keeping and a further third using standardised pro-formas (more common amongst social care practitioners). Pro-formas were helpful because of the structure they gave, but several had insufficient room for detail. **(7.1)**
- People often felt frustrated by how inadequately records were shared, even though their concerns sometimes hinged on a lack of understanding of the confidentiality of an IMCA report. **(7.2)**
- Best interests decisions for everyday matters were sometimes recorded informally, and we were told of systems to keep records in daily staff logs, or as a balance sheet attached to a care plan. **(7.3)**

The basis of the decision

- Both medical and social care decisions were often based on an assessment of risk. In social care decisions, protection and safety were key drivers, but respondents did sometimes mention having considered less restrictive options. A strong guide in making a best interests decision was a consideration of what a person did actually want, or would have wanted, if they had capacity to decide for themselves. **(8.1)**

- Creative thinking and finding good alternative options helped professionals to reach a decision in someone's best interests. **(8.1)**
- Decisions had to be made in the real world, and so often involved a degree of compromise, for instance in cases where a family carer's needs had to be considered alongside the best interests of the person lacking capacity. Best interests decisions often had to balance the needs of one person against another. **(8.1)**
- There were dilemmas for staff who were driven primarily by the need to respect autonomy in clients or patients, and felt concerned about overriding that autonomy. **(8.2)**
- Participants in this research felt they would benefit from more training, support and guidance about the MCA, which was specific and relevant to their profession. They also said they gained invaluable support from MCA advisors or local 'leads'. **(8.3)**

Outcomes

- Outcomes were related to particular decisions, and generally ran in the direction of protection or treatment being provided. However, in a number (10 out of 68) telephone cases, the decision had not yet been put into action. Lack of action happened because of a) professional failures in joint working; b) lack of resources or availability of a placement; c) refusals to comply, either by the person lacking capacity or by others; d) poor health condition of the person lacking capacity. **(9.1)**
- Good communication, sharing information and joint working were important factors for a good outcome. **(9.1 and 9.2)**
- The success of a best interests decision could only be known if there was a system for keeping in touch, or reviewing, how things were for the person lacking capacity. Family members, for instance, were well aware of the detail in their relative's life. **(9.2)**

- The Mental Capacity Act was felt to have given greater clarity to a confused area of practice, and was welcomed by most of our participants. **(9.2)**
- Although the MCA is primarily about individual autonomy and protection, nevertheless support and interrelationships with other people remained a key factor in the lives of individuals lacking capacity. **(9.3)**

Summaries of particular contexts for best interests decisions

Medical decisions (10.1.1)

- The telephone survey and interviews challenged the stereotypes of bad practice amongst health practitioners. Successful decisions about medical interventions were sometimes made through a multi-stage process, where consultation was carried out with those who knew the person, and the result was passed up to the senior medical practitioner, who had to take the final decision. Clear information about medical procedures was important, to help people get involved.
- In some of the successful practice we looked at, the social and personal interests of the patient were weighed up well. Strictly medical best interests did not always predominate, although they always did play a role in reaching the end decision.
- In some urgent cases, it was hard to carry out a full assessment of capacity. There was some evidence that summary assessments of a person's condition or diagnosis also informed other health care decisions. The difficulties of making a well informed decision about one's own health often tipped the balance in favour of an 'assumption' of incapacity.
- Record keeping in health care cases was mostly carried out by a 'detailed note'; however, this appeared to be an area requiring improvement.

Social care matters (10.1.2)

- Despite possible research sampling effects, it would seem that the MCA was most often being used in social care in relation to change of accommodation and safeguarding in a broad sense. By contrast, it appeared to be under-used in relation

to care reviews, direct payments and care planning, and also in everyday, routine best interests decisions.

- Best interests decisions in social care were most frequently carried out through a series of multi-disciplinary team meetings. Typical features of successful practice in social care decisions were good chairing and organisational skills, clarity in defining the decision to be made, and an overriding concern for engaging the client at the centre of the process.
- More junior staff in residential care, or in other professions, often deferred to senior practitioners to assess capacity. Capacity assessment in change of accommodation decisions were often carried out over a long period of time, and took account of fluctuations in capacity.
- Pro-formas for recording best interests decisions were more often used, and found to be useful, in social care cases. However, in everyday decisions it was more difficult to find appropriate ways to keep accurate records.
- Social care decision makers in general were strong in involving and persuading family members in sensitive ways.
- Outcomes in social care decisions were often dictated not only by the best interests process, but also by resources and eligibility criteria imposed by local authorities.

Property and affairs (10.1.3)

- Based on a smaller amount of evidence than for health and social care matters, decisions about property and affairs were often based on assessments of capacity carried out by a medical practitioner.
- Property and affairs decisions were often slow, considered processes. They were more likely to involve legal professionals than other matters.
- Property and affairs decisions were sometimes triggered by mistrust, or a suspicion of financial abuse.
- It was common for someone to lack capacity to make financial decisions, but to have intact capacity in other ways. However, there was a complex link between these decisions and other areas of people's lives, including social and health care needs.

People with dementia and best interests decisions (10.2.1)

- People with dementia accounted for 40% (154) of the cases discussed in the online survey. Most of the social care decisions about people with dementia related to a change of accommodation and only a minority related to safeguarding. They were less likely to have health or medical treatment decisions made for them.
- People who were frail, older and/or had a physical illness were sometimes found to lack capacity, although they did not have a diagnosis of dementia, and so would fail the Act's diagnostic test.
- Capacity assessments of people with dementia typically took place over a period of time, and involved repeated attempts to assess. However, there was some evidence of impairment related assumptions in assessing capacity, and standardized tests of dementia were mentioned as if they were tools for assessing capacity.
- The decision making capacity of people with dementia was often conflated with their executorial capacity (their ability to carry out an action, rather than decide on it).
- Outcomes for people with dementia were often limited by resources, availability of home care, and the need to consider relatives. Temporary admissions to care homes were sometimes made permanent, without the agreement of all parties concerned, and DOLS applications were only made in a minority of cases.
- On the whole, it appeared that people with dementia were somewhat disadvantaged in relation to capacity assessment and best interests processes, in comparison with other client groups.

People with learning disabilities and best interests decisions (10.2.2)

- People with learning disabilities accounted for 131: 34% in the online survey. Health care decisions were common, and the pattern emerged where a health deterioration or sudden need for treatment could reveal a raft of other issues, primarily relating to social care and/or accommodation.
- Those involved in best interests decisions for this group were likely to be part of a multi-disciplinary team.
- People with severe or profound learning disabilities were sometimes assumed to lack capacity. They may have been subject to one long-standing assessment, rather than being separately assessed for each decision.

- People with learning disabilities were sometimes thought to be making choices which put themselves at risk. There was a fine line here between lacking capacity and unwise decision making.
- Nevertheless, there were some good examples of successful assessment tools, specific to decisions. They were based on examining a person's ability to understand and communicate, as well as follow the implications of a decision.
- People with learning disabilities were less likely than other groups to be invited to best interests meetings, but they often had their views taken into account in other ways, including through: a) one-one communication; b) real life experiences and observation; c) accessible information. Person centred plans were mentioned in a few cases, as being very useful in helping with the best interests process.
- Family members and others were more likely to be consulted in decisions made in the best interests of people with learning disabilities, than for other groups.

People with mental health problems and best interests decisions (10.2.3)

- People with mental health problems accounted for 107 (28%) in the online survey. Typically, their best interests were considered in relation to their mental health needs, rather than in relation to physical health care needs.
- This group was more likely to face urgent situations, where their capacity had to be assessed at the scene, because they posed a risk to themselves or to others. Ambulance staff were likely to be involved.
- Several difficulties in assessing capacity emerged for people with mental health problems, including fluctuating capacity, the effect of mood on capacity, and a perception that being very vocal equates to capacity- when that is not necessarily the case.
- Successful processes for best interests decisions for people with mental health problems were often characterized by informality, quiet or calm contexts, and by the involvement of trusted and familiar people.

People with neuro-disabilities and best interests decisions (10.2.4)

- People with neuro-disability and those with brain injuries were under-represented in our research (75 or 19.5% in the online survey). This summary is therefore more speculative than that for other groups.

- Best interests decisions and the issues involved in capacity are likely to be distinct for the two groups, those with neuro-disability and those with brain injury.
- The sudden change in capacity in a person who has a brain injury continued to be hard to accept, even after a period of time, for those close to the person. For those with degenerative illnesses, the gradual deterioration in capacity can also make it difficult to assess when a patient has lost capacity to make a particular decision.
- Family members were regularly involved, and had strong and important roles to play in best interests processes.
- Clear information about medical decisions for this group was vital.

Recommendations

Recommendations for policy

- The Mental Capacity Act Code of Practice should be revised to enhance and clarify:
 - The distinction between unwise decisions and a lack of decision making capacity;
 - The distinction between “lack of insight” into one’s own care needs, and lack of decision making capacity.
 - Good practice regarding the interrelationships between adult safeguarding and best interests decisions;
 - Good practice in multi-disciplinary and multi-agency working involving complex, multiple best interests decisions and ‘consensus’ or joint decision-making, relating to an individual’s health and social care
- Case examples in the MCA Code of Practice should be developed to cover:
 - Assessments of capacity which reflect the complex, real-life situations and dilemmas in the current report.
 - Guidance on how to support an individual’s understanding of their own condition and support needs, before assessing capacity;
 - Best interests decision making in ward rounds, individual care reviews (e.g. Care Programme Approach), team care reviews and staff handovers (e.g. in care homes and hospitals), and key aspects of personalisation such as support planning and personal health/social care budgets, especially where there are ‘consensus’ or joint decision-making approaches.
- Terminology in the Code of Practice about roles in best interests decisions should be revised, to include the different positions taken by a best interests decision maker, a best interests leader and a chair person.
- Gaps in current practice, such as the possible under-use of DOLS, should be highlighted in the Code of Practice.
- Successful best interests practices should be listed within current guidance, including the MCA Code of Practice. These should include reference to the practice of separating out different ‘layers’ of decision making in best interests decisions, where a main decision leads to several sub-decisions.

- The Department of Health should, in consultation with health and social care providers, develop mental capacity assessment and best interests pro-formas that provide a flexible framework and guidance, and include a section for action planning. These should be added to the MCA Code of Practice as additional appendices.
- The Department of Health should review and update relevant risk guidance to take into account the way the MCA affects the management of risk.
- Department of Health policies and guidance about other areas of health and social care practice (e.g. care programme approach, personalisation) should be updated to reflect changes in the MCA Code of Practice recommended above. Guidance about best interests decisions, including the Code of Practice, need to remind practitioners to take into account the resources and services that are relevant and available in order that the decision can be implemented. Department of Health should ensure that resource constraints and eligibility criteria for services do not prevent health and social care providers from acting in accordance with the MCA in best interests decision making. Health and social care providers should record where resource constraints and eligibility criteria for services do unduly hinder the implementation of the Mental Capacity Act and CQC should monitor this.

Recommendation for commissioning

- MCA advisors or leads should be jointly appointed and funded by local authorities and health trusts, where they should have roles to support the implementation of the MCA across both statutory and non-statutory health and social care sectors.

Recommendations for professional education and training

- Training providers and local MCA leads need to develop more case examples about assessment of capacity and best interests decision making for the MCA Code of Practice, which reflect the complex, real-life situations and dilemmas in the current report, especially 'consensus' or joint decision-making approaches, and demonstrate how to avoid the common errors in assessment of capacity and best interests decision making.
- The Social Care Institute for Excellence (SCIE) should take into account the findings from this research when they review their MCA training materials and revise them accordingly, based on the different 'models' of decision making identified in this report. This should include the issues of sharing information, timing, delays in best

interests decisions-making, leadership, and the areas above recommended for revisions and case examples in the Code of Practice.

- MCA training materials and guidance need to be relevant and appropriate to the sector where they are being used rather than being based upon generic examples. Where these are not currently available (e.g. some specialist health settings) the relevant professional bodies should develop them.
- MCA training needs to be particularly addressed in mental health services; that training should clarify the distinction between the MHA and the MCA.
- Regulatory and professional bodies should ensure that assessing mental capacity and best interests decision making are core elements in the professional education and training of health and social care professionals. Education on the MCA should include open discussion about the professional dilemmas faced by health care.

Recommendations for practice management

- All providers of health and social care (including IMCA providers) and training providers should review and update their MCA policies, guidance, and training materials to reflect any changes made to the MCA Codes of Practice based on this research.
- All providers of health and social care (including IMCA providers) should undertake regular audits of compliance by staff and services with the MCA, including assessments of capacity, best interest decision-making, and DOLS, and carry out targeted training where non-compliance is identified. Completion of these audits should be monitored by the Care Quality Commission. The audits must include reviewing compliance in the following areas:
 - No individuals should be subject to a best interests decision where they have capacity to make the decision for themselves
 - IMCAs must not be involved in best interests decisions where family or friends of the person lacking capacity are being consulted (except in possible cases of conflict of interest or adult safeguarding)
- MCA local leads and commissioners need to find new ways to interact with care home staff and management, by more interactive, focused visits to discuss and improve practice in assessing capacity and managing everyday best interests decisions.

- Care home managers should institute a weekly review meeting, where assessments of capacity and best interests decisions for everyday matters within the home are reviewed. They should also ensure that care home staff receive training on assessing capacity and making best interests decisions so that they can undertake these themselves where appropriate, rather than contacting more senior staff or specialists for that purpose. Guidance for practitioners about the role of IMCAs needs to be reviewed and revised, with examples based upon real life situations where IMCAs have been involved.

Recommendations for future research

Department of Health, Ministry of Justice and other organisations responsible for research funding with an interest in the implementation of the MCA should fund further practice-related research.

- Given that the current research revealed the complexity of real-life decision making from the point of view of decision makers, it is important that further research is carried out to understand better the different perspectives of those involved in best interests decisions, including people lacking capacity themselves and their family carers.
- Assessment of capacity emerged from this research as the most difficult and sensitive area for practitioners, and it could therefore be followed usefully by more research about the practices involved in assessing capacity. For instance, it would be useful to examine everyday decision making, and also the practices involved in resolving disagreements and disputes that arise from capacity assessments.

1. Introduction and Methodology

1.1 Background

The 2005 Mental Capacity Act (MCA) in England and Wales is innovative in formulating a principled, legislative framework to protect the rights of individuals in decision making, in the assessment of capacity and the making of best interests decisions. According to the Mental Capacity Act, a person can be assessed as not capable of making a particular decision, in which case that decision should be made for him/her, according to his or her **best interests**. This situation has a direct impact on the rights of those people with impairments that might affect their decision making capacity, and in the current report, we focus particularly on those with dementia, mental health problems or learning disabilities.

Research about best interests decisions since the Act has highlighted confusions in practice (Myron et al, 2008), concerns about tokenism (Donnelly, 2009) and challenges relating to the resolution of conflicts (Joyce, 2007). Most of the research carried out about the MCA has been about individual aspects of the Act, and a set of resources was produced for SCIE (2008-9) on the basis of research in particular areas of the application of the MCA (McDonald, Dawson & Heath, 2008; Williams, Jepson et al, 2008; SCOPE, 2009). There are still several unanswered questions about how the best interests principle is being followed in general (Stanley and Manthorpe, 2008) and how it is interpreted in major life threatening situations (Hegde et al., 2006).

The current study (BIDS) was therefore funded by the Policy Research Programme (PRP) at the Department of Health, three years after the implementation of the Mental Capacity Act, in order to examine the professional practices involved in best interests decision making. The study was carried out by a multi-centre research team from the University of Bristol, the University of Bradford and the Mental Health Foundation. The purpose of BIDS was to gain robust information and understanding of the extent to which the law on Best Interests and the associated MCA guidance was being implemented in a wide variety of settings. In this opening section we will outline the aims of the study, with some brief points about the methods used and the implications of the sampling we undertook.

1.2 Aims of the study

The central goal of this study was to provide a picture of practice according to the main contexts and types of decisions being made (health care, personal welfare and property and affairs), and relating to different groups of individuals. Within this overall research goal, several questions were addressed:

1. In which contexts are best interests decisions formulated, and for what groups of individuals?
2. What is the range of current practice models for making best interests decisions, and is there any association between any of these models and particular contexts?
3. How is capacity being assessed, and what prompts such assessments?
4. How is extant decision making by the person lacking capacity being facilitated?
5. What factors are taken into account by those who make best interests decisions, and how are these factors considered?

In particular, the research aimed to identify clearly the processes of determining best interests in detail and potential barriers and obstacles that face all those involved in best interests decisions. Therefore a second set of questions included the following:

6. How are the personal views and beliefs of the person lacking capacity examined?
7. How are the views of relatives and carers, professionals and panel members weighted against the objective factors involved in weighing up outcomes of decisions?
8. What influence, if any, do resource allocation mechanisms have on the eventual outcome?
9. What challenges do professionals face when making best interests decisions?

These aims were seen as a guide to investigating practice in best interests decision making. Our intent was to have a design that would be as open as possible, so that we could discover how practitioners were implementing the best interests aspect of the MCA. We sought a design that would not constrain that goal, but would enable us to systematically explore practice in as wide a range of contexts as possible. It was impossible to quantify the extent to which the MCA was being implemented without a national survey. The current study design, however, allowed us to discover more about the patterns of practice rather than the overall quantity of best interests decisions.

1.3 Summary of methodology

This was a multi-stage, mixed methods project, which took place in four areas in England, described below in Section 1.4. An initial focus group stage is reported elsewhere (Appendix F)) in which we identified questions that might be important from the point of view of the major impairment groups involved in the research, and also from the point of view of the major professional groups. Following that, the three stages of the study were:

- **Stage 1 – online survey (reported in BIDS analytical report 1)**

We aimed to recruit 400 people to participate in an online survey, and achieved 385.

- **Stage 2 – telephone survey (reported in BIDS analytical report 2)**

Our target was 70-100 people to take part in a telephone interview. We achieved 68.

- **Stage 3 – face to face interviews (reported in BIDS analytical report 3)**

We sought to recruit 20-25 ‘cases’ to follow up in more detail using face to face interviews, and achieved 25 cases.

We refer to these three analytical reports as Reports 1, 2 and 3 throughout the current final report. The mixed methodology design allowed for a large amount of information to be gathered first through the online survey (Stage 1), followed by a ‘funnelling’ process whereby we were able to gather progressively more detailed information about the process and the issues involved in best interests decision making. The telephone survey (Stage 2) consisted of interviews following a structured protocol, in which we were able both to check more detail about the processes followed in best interests decisions, so that these could be explored further in face-to-face interviews at Stage 3. The plan at this third stage was to carry out separate interviews with different people (professionals, family or others) who had been involved in each of 25 best interests cases, and we achieved multiple interviews for 12 of our 25 cases.

An advisory group was recruited from national organisations representing the different impairment groups involved in the research, as well as the Office of the Public Guardian (OPG), practitioners and policy makers. Three meetings were held during the course of the project, and members of the group were active throughout in checking materials, providing practical assistance and advice. Their names are listed in the front of this report.

1.4 Ethical approvals

We gained approval for this study from a 'flagged' NHS REC. This was necessary for two reasons. Firstly, this research involved a sample drawn from NHS staff; secondly, people who may lack capacity to consent to the research could have been included in the face to face interview stage. The research was approved after minor amendments to study documentation, by the Essex 2 Research Ethics Committee on 11 June 2010 (study REC reference number: 10/H0302/23). Following favourable ethical review, the study then sought, and gained Site Specific R&D approval from each of the NHS settings.

As the study also took place in local authority settings, we applied to gain the support of the Association of Directors in Adult Social Services (ADASS) research group. Confirmation of support from the research group was received on 10 August 2010 (ADASS code: Rg10-014).

1.5 Sampling

We sought four areas in which to situate the BIDS research, which had reasonably differentiated profiles, representing the spread of ethnicity, socio-economic status and living conditions across England and Wales. For anonymity, we have not used the names of the areas. Areas 1 and 3 are metropolitan districts, and areas 2 and 4 are counties.

Table 1: Demographic profiles of the four areas selected in the study

	Area 1	Area 2	Area 3	Area 4
Population figures (ONS mid 2008)	501,700	710,500	287,500	1,109,700
Proportion of population over the age of 65	20%	26%	16%	16%
BME population as a proportion of total (2001 census)	18%	3.2%	23%	5.1%
People registered as non employed, and permanently sick or disabled	6.1%	3.5%	7.4%	2.4%
Density of population (ONS mid 2008)	1290 people per km ²	160 people per km ²	3379 people per km ²	667 people per km ²

Our aim in selecting areas for this research was to represent the spread of socio-economic and cultural diversity in the country. We were able with these four areas to sample both rural and urban populations, with the density of population differences indicating the very different living conditions of people in Area 3, for instance, compared with Area 2. The overall national figure for those who were permanently sick/disabled in 2001 was 5%, so we can see that two of our areas (Area 2 and Area 4) fell below that figure, with Area 1 and Area 3 both having higher populations of those who were registered as sick/disabled. In general, it can be seen that Area 1 and Area 3 had relatively similar profiles, with high ethnic minority populations, high density of population and a relatively large number of people who were registered unemployed and had a disability and/or sickness. Area 4 was an area with a much larger population overall than Area 2, seemingly related to the density of population there, which is higher than Area 2. Thus in Area 4, we see an area which has more urban development than Area 2, and fewer people over the age of 65 by comparison with Area 2, which is a popular retirement area with a high density of care homes.

Within the four areas, we gained Research and Development permission to access staff from 14 NHS Trusts, and 4 local authorities. The participating organisations are shown in Table 2 below.

Table 2: Participating organisations in the four areas

Area	Trust / Authority
Area 1	Area 1 District Care Trust
	Area 1 NHS Foundation Trust
	Area 1 PCT
	Area 1 Teaching Hospitals NHS Trust
	Area 1 Ambulance Service
	Area 1 Metropolitan Borough Council
Area 2	Area 2 PCT
	Area 2 Hospital Foundation Trust
	Area 2 HealthCare NHS Foundation Trust
	Area 2 County Council
Area 3	Area 3 Primary Care Trust
	Area 3 Mental Health and Social Care Foundation Trust
	Area 3 Metropolitan Borough Council
Area 4	Area 4 PCT
	Area 4 Healthcare Trust
	Area 4 Ambulance Trust
	Area 4 Social Care NHS Trust
	Area 4 County Council

1.6 Research protocol

A self-complete online survey was developed which asked respondents about a specific best interests decision making process. In developing the survey, care was taken to base questions on MCA guidance, both about assessment of capacity and about best interests decision making. The survey was discussed with members of the advisory group, who helped us to ensure that it covered all relevant aspects, and it drew on the format already successfully developed by the Mental Health Foundation for assessing capacity. The survey was posted online (at: www.bestinterests.org.uk). We sent a link to this web page to the lead contact in the NHS Trusts and local authorities in the four study areas (see 1.4). In addition,

in the four areas we promoted the survey to care homes, to the main IMCA provider organisations and to legal firms, via a link from the Solicitors for the Elderly database. Recipients were asked to cascade this link, along with a project information sheet, widely among their teams. Potential participants were free to decide whether to complete the survey. Those who did elect to complete the survey were given a further option to consider whether to submit their responses to the research.

At the end of the online survey, respondents were asked to indicate whether they would consider taking part in a telephone interview. After providing additional information and negotiating consent, telephone interviews were arranged.

At the end of the telephone interview, participants were asked whether, in principle, they would be prepared to talk in more detail about a specific case. Those who said that they would be prepared to take part further formed the population to be sampled for the final stage of face to face interviews. We developed a sampling grid with the aim of capturing examples for the different types of decision, and for each of the main impairment groups identified. When we contacted participants, we explained that they could either tell us more about the case they had already discussed, or that they could choose a new one. We also asked them to pass on information and consent forms to others who had been involved, so that we would be able to obtain multiple perspectives on the same best interests process.

The shape of the research design resembled, in some respects, a funnel. It was essential that participation in the online survey proceeded as swiftly as possible, in order to populate the subsequent phases of the research. Several of the key contacts in local areas were extremely helpful in promoting the research locally, and the MHRN was also very helpful. However, despite this, several sites experienced difficulties in prioritising the research initially, and this had the inevitable effect of slowing the progress of the research project as a whole, resulting in some difficulties during the final stages of the work.

1.7 Data and analysis

Data from the online survey were extracted from the web server and analysed using SPSS¹ for descriptive and inferential statistics. Telephone interviews were designed in a structured format, with open-ended questions which allowed for greater detail and development of topics. All of the interviews were recorded directly onto pro-formas, so that demographic detail and quantitative data could be collected. Those data were also analysed using an SPSS spreadsheet. However, during the course of this stage of the research, it became apparent that the qualitative data from telephone interviews would yield a richer analysis than we had at first thought. Forty nine of the interviews were audio-recorded and transcribed, while the remainder were recorded in written format. A systematic qualitative thematic analysis was therefore carried out using a qualitative software package (NVivo).

The topic guide for the face to face interviews was drafted as a result of emerging findings from previous stages of the research and sought to follow through some of the major ideas and themes that had already emerged about best interests processes. In most cases, we were able to build the face-to-face interview on information and questions raised in the telephone interview. We produced a separate interview schedule for a) the decision maker; b) another professional involved in the best interests process; c) a family carer. These are all given in Appendix B of Report 3. The interviews were audio-recorded and transcribed. A systematic qualitative analysis was carried out, following broadly the main substantive headings of the research questions, but within those headings exploring issues from the point of view of participants themselves, allowing codes to develop from the data. We made use of a qualitative software package (NVivo), which allowed us additionally to categorise the interviews and examine data in particular groups, such as health care decisions, or cases relating to people with a particular impairment.

1.8 The participants

a) Stage 1 - online survey

There were 392 responses to the online survey. Almost three-quarters (283; 72%) of the respondents were female, with 107 (27%) being male. Two respondents did not report their gender. The age of the respondents ranged from 20 – 69. The grouped age categories are given in Table 3.

¹ Statistical Packages for the Social Sciences

Table 3: The age of the respondents to the survey

Age group	Number	Percent
18-29	36	9
30-39	81	21
40-49	145	37
50-59	94	24
60 and over	23	6
Missing	13	3
Total	392	100

The majority of respondents were of White British ethnicity (85%), with no other ethnic group comprising more than 6% of respondents. Over half of the respondents (238; 60.5%) worked within the NHS, the largest proportion working within a mental health/learning disabilities Trust (134; 34%). Those describing ‘other’ employers included those who had retired, were self-employed, or worked for non-specific employers such as a ‘care home’. A full breakdown of the respondents’ employers is shown in Report 1, Table 2, while Table 3a below shows the respondents’ professional sectors:

Table 3a: The respondents’ professional sector

Professional sector	Number	Percent
Healthcare professional	259	66
Social care professional	77	19.5
Care assistant/support worker	15	4
Family member	12	3
IMCA	7	2
Court appointed deputy	4	1
Legal Advocate	3	<1
LPA property and affairs attorney	1	<1
Other	7	2
Missing	7	2
Total	392	100

There was evidence of some uneven representation of our target professional sectors. For instance, corporate deputies and legal professionals were under-represented. These matters were discussed with the project advisory group, where it was agreed that the project would not seek to focus on those who had lasting power of attorney, where they were lay people and family members. However, deliberate attempts were made at this stage to redress the

balance for the subsequent stages of the project, by recruiting solicitors directly through ‘Solicitors for the Elderly’, who were represented on our advisory group. Unfortunately, despite the OPG representation on the same group, we were not so successful in recruiting corporate deputies.

b) Stage 2 - telephone survey

We achieved 68 telephone interviews, thus almost reaching the target, and were satisfied that we had reached sampling saturation. Participants in telephone interviews were recruited from those who volunteered after filling in the online survey. Inevitably, this design favours those with the most ‘positive’ practice, since they were the ones volunteering to take part. Nevertheless, within this report we were able to explore more closely some of the issues which underlay the general points noticed in the survey.

The four geographical areas in the study were very different in size and scope, but the final numbers attained from each site were relatively even, as shown below in Table 4. 59% (n=40) of the telephone interviews worked for an NHS Trust and the next biggest employer were local authorities (21%, n=14).

Table 4: Telephone interviews carried out in each site

Area 1	20
Area 2	17
Area 3	13
Area 4	18

The majority of telephone interviewees were female (64%), and white British (91%). The age range of telephone interviewees is shown in Table 5 below:

Table 5: Age of respondents in telephone survey

Age of respondents	Number	Percent
18-29	3	4%
30-39	8	12%
40-49	29	43%
50-59	17	25%
60 and over	9	13%
Missing	2	3%
Total	68	100%

From the telephone interviews, we were able to find out more detail about respondents' professional roles, and the breakdown of those roles is shown in Table 5a. As will be seen, some efforts to redress the imbalance of professional roles were made, resulting in telephone interviews with three solicitors' offices and one appointeeship unit (acting also as corporate deputies). All were followed up at the subsequent interview stage.

Table 5a Role of respondents in telephone interviews

	Area 1	Area 2	Area 3	Area 4	TOTALS
Health clinician	1	1	1	1	4
Nurses	2	3	2	4	11
PAMS	1	1	2	1	5
Staff in long stay hospitals or nursing homes	1	2		1	4
Residential home staff		2	2	1	5
Social care professionals	5	3	1		9
Legal		1	1	1	3
Mental health	5	2	2	3	12
Psychologist				2	2
Ambulance staff	4			2	6
Family member or friend	1	2	1	1	5
IMCA				1	1
Appointees office			1		1
	20	17	14	18	68

c) Stage 3 - face to face interviews

At the face to face interview stage we achieved the target of discussing a total of 25 'cases'. The geographical spread of these 25 cases is summarised in Table 6 below.

Table 6: Face to face interview ‘cases’ in each site

Area	Cases
Area 1	5
Area 2	9
Area 3	4
Area 4	7

In 7 of these cases, we were able to interview more than one person involved. In total we spoke to 44 respondents (some in joint interviews). The goal here was to obtain different points of view about the same best interests process, and, although the original research tender focused on professionals’ practices, we had planned to include family members at this stage of the research. However, we encountered considerable problems with this. First, the decision makers we approached, even when agreeing to be interviewed themselves, were reluctant to pass on information to others who had been involved. In particular, they often said that carers and family members would not want to be reminded of the process, and still had considerable problems to deal with. Secondly, the data collection phase for this part of the project was simply too short, given the initial gatekeeping difficulties and delays in recruiting both sites and participants. Therefore, we had reluctantly to concede that we would not be able to obtain the views of carers, other than those few cases in which a professional interviewee described to us a case relating to a relative. A decision was made therefore to include a larger number of IMCAs, since they were more likely to have in-depth information about the person lacking capacity and to stand in for a ‘family viewpoint’.

We therefore made particular efforts at this point to fill gaps in our sampling, not only in relation to IMCAs, but also in relation to care home staff and legal professionals, including corporate deputies. Building on our efforts in the telephone interview stage, where we presented at local events and also arranged visits to care homes to talk about the Mental Capacity Act, we were able to include six residential or care home staff at this stage. We also made particular efforts to recruit IMCA participants, via the national IMCA conference. As Table 6a illustrates, we conducted at least one interview within each of our major groups of professional roles, with the exception of ambulance staff.

Table 6a Role of respondents in face to face interviews

Role of Respondent	Area 1	Area 2	Area 3	Area 4	Total
Health clinician		1			1
Nurses	2	2			4
PAMS		2	2		4
Staff in long stay hospitals or care				1	1
Residential home staff	2	4	1		6
Social care professionals	1	1		2	4
Legal				6	6
Mental health	2				2
Psychologist				1	1
Ambulance staff					
Family member or friend				1	1
IMCA		4			4
Other*	1	1	4	3	9
Total	8	15	7	14	44

*Those classified as 'other' were: 2 service managers, 2 appointees, a palliative care coordinator, and a safeguarding coordinator in a hospital trust .

1.9 Types of decision

At each stage of the research, we asked participants to define the category of the decision that they had been involved in making. Initially, in the online survey, respondents were limited by the categories: Health, Personal Welfare, Property and Affairs or other.

Respondents were also able to select the category 'More than one type of decision'. We used these same categories for the telephone interviews, but were able to categorise each case according to the actual subject of the decision as discussed with the interviewee, rather than relying on respondent choice. At the face to face interview stage we further categorised the personal welfare decisions into: social care, change in accommodation (discharge) and change in accommodation (other).

The number of respondents / cases in each of these categories is shown in Table 7:

Table 7: Respondents / cases according to decision category

Type of decision	Stage 1	Stage 2	Stage 3
Health	184 (48%)	21 (31%)	6 (24%)
Personal Welfare* (sub-divided at stage 3)	93 (24%)	37 (54%)	15 (60%)
• Social Care			5 (20%)
• Change in accommodation (discharge)			4 (16%)
• Change in accommodation (other)			6 (24%)
Property/ affairs	28 (7%)	9 (13%)	4 (16%)
More than one matter	78 (20%)	1 (0.01%)	0 (0%)
Other	2 (1%)	0 (0%)	0 (0%)
Total	385	68	25

As seen in Table 2 above, in total 14 NHS Trusts were involved in the study but only 4 local authorities. Consequently, there is a bias towards health care employees in the study, with over half of the respondents (238; 60.5%) to the online survey working within the NHS (Report 1, Table 2) and a similar proportion (40: 60%) of the telephone interviewees employed by NHS Trusts. However, as we discuss below in 2.1, whilst a large proportion of respondents identified that the type of decision they had been involved in was ‘health care’ this in fact represents a broad range of different decision types.

1.10 Numbers of cases relating to each impairment group.

Further demographic information was collected about the impairment of the person for whom each best interests decision was being made. In Stage 1 – the online survey – respondents were able to select more than one category hence, in Table 8 below, the total number of responses exceeds the number of survey respondents.

Table 8: Respondents / cases according to impairment of the person lacking capacity

Impairment (either on its own or in combination with other impairment(s))	Stage 1	Stage 2	Stage 3
Dementia	154 (40%)	29(43%)	8 (32%)
Learning disability	131 (34%)	24 (35%)	9 (36%)
Mental Illness	107 (28%)	11(16%)	5 (20%)
Neuro-disability	75 (20%)	1(1%)	2 (8%)
Intoxication due to alcohol or drugs	21 (6%)	3 (4%)	0
Lack of consciousness	17 (4%)	0	0
Other	5 (1%)	0	1 (4%)
Total	510	68	25

It is important to note certain factors about the overall sample, which have a bearing on how this report should be read. Firstly, the sample included more cases relating to people with dementia and learning disability, with lower numbers relating to those with mental health problems and neuro-disability, particularly at the later stages. That could mean that the MCA is being used less with those particular groups, but the bias could also have arisen partly from the sampling strategy and the range of trusts approached. Secondly, by comparison with the cases relating to people with recognised impairments, we have far less information about the wider application of the Act in relation to people who do not have an 'impairment', but have suffered loss of consciousness or intoxication. That could well indicate that the MCA is used less in those circumstances, since our sampling strategies should for instance have ensured that we had cases relating to patients in acute care or emergency situations. It should also be noted that this report on the whole represents best interests decision making which is confident and well-informed, compared with a random sampling design. Over three-quarters of the telephone interviewees (54: 80%) told us that they had been using the MCA since its inception. Whilst this statistic does not tell us about their understanding or application of the Act, we can see that there is a familiarity with the legislation in our sample. Further, the data we gathered from each stage of the research was predominantly about serious, 'large' decisions, rather than about everyday best interests decisions which take place under the MCA. We were able to deliberately sample some of the latter in the final stage of the research, as will be explained in section 4.4.6. However, the bias towards major decisions may also represent a general feature of the state of practice and application of the MCA, some four years after its inception.

This report is organised according to the logical process of best interests decisions. Each section of the report draws on evidence from all three stages of the research, and references to particular analytical reports (Report 1, 2 and 3) are made throughout, in order to ground this discussion in the data and analysis. Section 2 explores the reasons and contexts for best interests decisions, analysing the triggers that have led to practitioners undertaking a best interests process. Following that, we look at assessments of capacity in Section 3, and then the processes used in determining best interests, including informal and formal structures, in Section 4. Section 5 continues building a picture of the process, with our findings about how people's views and wishes were included, and how others close to the person were consulted. Section 6 provides an account of the information we had about the role of IMCAs, and Section 7 then turns to record keeping and information strategies. In Section 8, we review the way in which best interests were actually determined, and what helped people in that process, and Section 9 goes on to examine actions and outcomes. Finally, Section 10 goes back through the analysis to draw out the key issues and trends for the different major contexts of health, social care and property and affairs, and finally the key issues and trends for different impairment groups. Readers who have particular interests in one sector may wish to turn to the relevant part of Section 10 first. Our report concludes in Section 11 with some overall reflections on the major findings, and a discussion of the practice and policy recommendations that arise from this research.

2. Triggers for undertaking a best interests process

2.1 The need for health treatment

Best interests decisions in the online survey were classified broadly, according to the responses to a question asking what the best interests decision was about. The options included the major contexts of best interests decision making, including an option for 'more than one matter' and 'other'. Of the 385 valid responses to the survey, it can be seen from Table 7 above almost half (48%) of all decisions were made regarding health care. A quarter (24%) were about personal welfare or social matters, and a slightly smaller percentage (20%) were about more than one matter. Just 7% were about property or financial matters.

No claim is made that those figures are representative of the proportions of best interests decisions across the country; the large number of health care decisions could simply represent the bias towards health contexts in the sampling strategies used in this research. Nevertheless, it is interesting to investigate further what each type of decision was about, since that can start to tell a story about where the MCA is being considered. Table 9 below shows the breakdown of health care decisions into sub categories.

Table 9: Different types of health care decisions in online survey

Type of decision	Number	Percent
Consent to serious physical healthcare treatment	74	40
Another decision concerning physical healthcare treatment	61	33
Consent to serious psychiatric treatment	14	8
Another decision concerning serious psychiatric treatment	4	2
Other	31	17
Total	184	100

Of the 184 health care decisions represented in the online survey, 40% were in fact about consent to serious physical health care treatment, while a further 33% were about 'another decision concerning physical health care'. Looking in yet greater detail at those serious physical treatment decisions, it was found that fewer than half (31; 42%) were about life sustaining treatment. Further, about a quarter of all the treatment decisions were being made in the context of a care home or hospital, and were associated with an assessment for a DOLS. A similar number involved people who were resisting psychiatric treatment, and

almost half of the treatment decisions involved restrictions being put on the person, including the use of medication or staff control over the person. These were simply descriptive statistics; nevertheless they provide some clues to a picture of health care decisions that became more differentiated in the telephone survey and the interview stage.

Report 2 (the telephone survey) followed up in more detail the triggers for a best interests process, and Section 3.1.1 in that report shows that serious deterioration in physical health was often cited as the start of a best interests process; the typical pattern was that the person in question was resisting treatment, and some interviewees mentioned that the trigger for the best interests process was the difficulty they foresaw in gaining consent, particularly with people with learning disabilities or mental health problems. In other cases, the risks of the treatment had also to be balanced against the psychological wellbeing or quality of life of the individual, for instance in the case of decisions about artificial feeding or about other invasive procedures. A case that was followed up from the telephone survey and also in the interviews is given as an illustrative example here:

A man with profound learning disabilities, living in a care home, was at risk of aspirating food, and had been considered for artificial feeding by inserting a PEG tube. The home manager explained that this patient had been 'in and out' of hospital, due to respiratory problems, and the consultant had therefore insisted that he be recommended for artificial feeding, for his own safety. However, his health needs had to be balanced against a raft of other factors, notably his liking for food and the possible dangers of inserting a PEG tube. His parents strongly felt that the operation was not in their son's best interests, and a process was undertaken where all parties, including the nutrition consultant and specialist nurse, shared information and views. The outcome was that artificial feeding was decided against. (T03 in Report 2; F01a and F01b in Report 3).

Particularly at the interview stage (Report 3, Section 2.2), it became apparent how easy it would have been for the medical judgement of the respiratory consultant to hold sway in the case above. The medical practitioner in the acute hospital tended to identify only the medical need itself, while care home staff then had the task of considering the issues and effectively bringing a medical decision into the arena of 'best interests'. The man's health condition, in other words, had escalated to a point at which action was necessary. At that point, it was the staff and family in this case who started to discuss whether that would in fact be in the man's

best interests, since food was so important to his quality of life.

The critical role of care home staff, family and others who are close to the individual was a major theme in Report 3. The person who identified the medical need was often a nurse, or a member of staff in a care home. They were then dependent on initiating a discussion with medical practitioners, or experts in the particular field and much depended on how this conversation proceeded. It is important to note that nothing would happen in many cases, if care staff were not aware that things had passed a critical point.

Restrictions due to psychiatric needs were also explored in the interviews. In F10, for instance the residential home staff had identified a mental health problem in one of their residents, which seemed to be exacerbated when her visits to her sister were too long. They sought therefore to restrict the length of those visits, by carrying out a best interests process. It was also noted by several participants, including occupational therapists, specialist feeding nurses and a palliative care nurse how important it was to look beyond the strictly medical needs of the patient. There was a strong emphasis on getting to know the patient well, and on looking at their life in a holistic way, not just at their medical symptoms.

Some types of health treatment decisions, however, were triggered by urgent situations. Table 10 shows that in 54% of health care decisions, the assessment of capacity had to be made on the same day as the best interests decision.

Table 10: The timing of the assessment of capacity, when considering the type of decision needing to be made (from the online survey)

Time when assessment of capacity was made	Healthcare % (n=178)	Personal welfare/ or social matters % (n=84)	More than one matter % (n=75)	Property or financial affairs matters % (n=26)
On the same day as making a best interests decision	54	42	48	39
Up to a week previously	7	14	8	15
More than a week previously	22	25	35	31
Over the course of several weeks	9	11	5	0
Not known/not sure	8	8	4	15
Total (%)	100	100	100	100

In section 3.1.2 of the second analytical report we mentioned some of those urgent medical situations, including a drug overdose, and a fall experienced by an older woman living alone. There was also an urgent decision to be made in the context of an intensive care unit (Report 2, 3.1.2) in which a person’s life was at stake. Urgent situations were often confronted by ambulance staff, at the point when someone had to be taken to hospital, possibly against their will or without their consent. Although we only had 26 respondents in the online survey who identified as ambulance staff, and six in the telephone survey, they nevertheless held key roles both in assessing a person’s capacity and deciding whether or not to follow a best interests process.

If a best interests process could be triggered by an urgent or non-urgent deterioration in health, it will be recalled that 33% of the health care decisions were classified in the online survey as ‘another decision regarding health care’. In the telephone survey and interviews, it emerged that many health-related decisions could turn out to be rather mixed (Report 2, 3.1.1). We will explore next those that related specifically to changes in accommodation or discharge from hospital.

2.2 The need to move

A health deterioration, or the need for a health intervention, could reveal a catalogue of other problems, including social needs which led to a best interests decision. For instance, in the telephone survey (Report 2, 3.1.1), a man with severe learning disabilities was described (T08) who lived with his ageing mother. The situation was far from ideal, since his mother herself had considerable health needs. However, he then had to undergo an emergency operation for a hip replacement, and it was realized that his mother would no longer be able to care for him at home. As the interviewee commented:

It's the old saying ...everything just hobbles along until some event happens, like this, and suddenly you realise that this has been hobbling along [T08]

A large category in the data concerned decisions about discharge from hospital. Table 11 shows that 41% (38) of those described as personal welfare or social matters in the online survey concerned a change in the person's accommodation involving a move into or out of a care home, and a total of 41% of the total cases related to change of accommodation.

Table 11: The types of personal welfare or social matters involved in the online survey

Type of decision	Number	Percent
A change in the person's accommodation involving a move into or out of a care home	38	41
Adult safeguarding	15	16
An 'everyday' issue such as what to eat	6	6.5
Intimate personal care such as washing	5	5.5
A care review	5	5.5
A change in the person's accommodation NOT involving a move into or out of a care home	5	5.5
A significant social care event such as going in holiday	3	3
Other type of issue	16	17
Total	93	100

However, in the telephone survey, we had proportionally a greater number of these cases, in that 18% (12) of the 68 decisions discussed related to change of accommodation generally, and a further 23% (16) related to discharge from hospital. Change of accommodation also featured in the interview stage, with four cases relating to discharge from hospital, and a further six relating to other changes in accommodation (See Table 11 above). This category represented in all 40% of the 25 cases covered in the interviews). This

'bulge' in the later stages of the research would lead one to suspect that some of the 'other' category in health care decisions in the online survey would have been filled with those discharge decisions. The fundamental driver for these decisions was the need to free up a bed, and they were triggered by the need to move people on, from long-stay hospitals, geriatric hospitals, acute hospital care, or psychiatric wards. One interviewee in Report 2 (3.1.1), a staff nurse who had befriended a man with learning disabilities, said:

The main hospital – the acute care hospital just wanted him out because they needed the bed. The community hospital just wanted him out because they needed the bed.
[T08]

A spell in hospital can of course change a person's needs and outlook, and a common situation was for someone with dementia to be admitted to acute hospital care, from which they then recovered sufficiently to be discharged. In the online survey, it was found that people with dementia were significantly more likely than those without dementia to have decisions made for them about a change in accommodation involving a move into or out of a care home (see Report 1, Tables 19 and 20). These situations seemed to arise particularly after a stay in hospital, after which the problem then arose about whether their physical and mental needs would be met at home. For instance, in the telephone survey (Report 2, 3.1.1), a cognitively impaired older lady living in sheltered housing with her husband was admitted to hospital with an infection. As there were concerns about her safety (she had been "wandering" out via the fire exit and had had several near misses with the traffic), the decision was whether to admit her to a care home.

It seemed therefore from our telephone interviews that it was quite hard to divide best interests processes neatly into health or social care. This complexity was explored further in the face-to-face interviews. As explored in Report 3, Section 2.1, the cases regarding a change of accommodation were seen to potentially impact on the physical as well as the social wellbeing of the client and their carers through such issues as the provision of a more supportive and hygienic living environment or through the reduction of carer 'burden':

So there was an element of looking at reviewing medication and healthcare and psychiatric care if you like, as well as social care and support for her carers. (F25a)

Three cases regarding self care, while obviously focusing on the health of the client, could also be seen as having a social aspect, since provision of personal care could enhance the person's social acceptability. In one case (F21a) it was felt particularly to focus on this issue, to enable the patient himself to appreciate the value of cleanliness, hygiene and regular food. Thus we can see that not only the professionals, but also the person lacking capacity, may be led to focus on their lifestyle generally, through a hospital admission or a change in their circumstances. As may be expected, these issues were often complex, and social care staff, for instance, frequently mentioned multiple problems, which had built up to a critical mass and forced them to act. The availability of resources as well as the degree of risks involved could have an impact on the perceived urgency of the decision about a move. For example, the urgency of F25 in the telephone survey (Report 2, 3.1.1) was downgraded from very urgent to fairly urgent following the client's admission to respite care:

Some of the urgency was removed because the lady was in a residential placement that was meeting her needs and she was safe and well cared for. So many of the risks she and the carers had faced at home were not immediately present, but could be expected to arise.(F25a)

It should be noted here that the complexity of separating out health from social care and other needs possibly led to a situation in which respondents considered more than one decision about a person at the same time. It will be recalled from Table 7, that 78 responses in the online survey indicated that the best interests process was undertaken 'for more than one decision'. That could indicate an area where there is some misunderstanding of the decision specific nature of the MCA, but the cases which we followed up in depth were in fact generally clear about defining and separating out different aspects or different decisions relating to one person.

2.3 Being unable to manage safely

If a very common trigger for considering a best interests process was a change in accommodation, it can be appreciated from the examples above that this was often linked to a consideration of the risks faced by an individual lacking capacity. As seen above in Table 11, fifteen (16% of the social care decisions in the online survey) were reported to be about adult safeguarding. Ten (15% of the 68 telephone interviewees: Report 2, 3.1.2) described a

situation in which there was a safeguarding concern, and an additional two where the concern was about safeguarding financial interests.

In at least 28 of the telephone interviews, the risk described was of an urgent or immediate nature, and it the best interests process was precipitated by a crisis, as seen in Section 3.1.2 of Report 2. For instance, in one case, a young man with a learning disability was living in a residential learning disabilities unit and his sister visited regularly to take him out in her car. She had difficulty transferring him to and from her car and there had been an accident; the decision then was whether or not it was still safe for the arrangement to continue (T51). One woman had a psychotic episode and attacked her son; another person was described who had taken an overdose, and a woman with dementia had locked herself into her own home, with the oven on.

However, some of these crisis situations had a long back story and were very complex, as illustrated in Section 2.1 of Report 3. Participants in interviews tended to speak about a catalogue of events that had led to the problem in question. A best interests process was not often undertaken in relation to one-off risky incidents, but it was about repeated attempts to protect people from themselves, which had culminated in having to take slightly more formal action. In the interview sample, we explored the issues of people who refused to care for themselves, people who wanted to go out at night (as in F09) or people who wanted to spend their money unwisely (F07; F15). All these individuals already had care and support in order to manage what were seen as unsafe behaviours. However, up until this point, those behaviours had effectively fallen into the category of 'unwise decisions'. A case study about risk is analysed in Appendix A of Report 3, but for illustrative purposes here is a short version.

A 39-year-old man with moderate learning disabilities was living in a group home, with support for a few hours during the day provided by an agency. He had long been considered vulnerable, since he had formed relationships with people who were selling him drugs, and he tended to go out at night to meet with those friends, despite the attempts of staff to instil in him a sense of his own safety. He had a long period of counselling with a psychologist, and was then the subject of formal safeguarding meetings, where it was considered that it would be in his best interests to live in a more protected environment. As he did not want to do this, however, his capacity was assessed in relation to his understanding of safe drug use, and

also in relation to the proposed move. It was agreed that he did not have a full understanding of the risks he was facing, and so it was decided that he would have to be persuaded to move into a home with 24 hour support. (F09, Report 3)

Essentially, the majority of cases relating to a change in accommodation, particularly for people with dementia, were also about the risks they would pose to themselves if living on their own. It was rare to hear about a best interests process that had resulted in a *less* protected living situation, although it did occur three times in the telephone survey and interview stage, where people with learning disabilities were moving into their own flat or into supported living accommodation, and in the interview stage, where a man with learning disabilities was described who was moving out of a secure psychiatric ward, and back into his own flat (F07). In those cases, what seemed to trigger the best interests process was not only the need to move, but also a consideration of the specific risks that the person might face. The capacity to make a decision about living independently might have been intact, but on closer inspection, it was seen that the man moving out of the psychiatric ward *did* lack capacity to make decisions about paying his own bills and managing his rent. This risk was particularly evident to his parents, and time was spent in assessing the man's capacity, and talking with him about how he would manage once he moved back to his own flat. In the end, that resulted in the decision to manage his bills via a corporate deputyship.

Safety and risk factors were often interwoven, then, not only with both health and social care decisions, but also with financial aspects of decision making. Decisions about property and affairs were under-represented in the online survey, amounting to only 7%, or 28 of the 385 cases, as seen above in Table 7. However, in subsequent stages, cases were identified in which a social care decision was sparked originally by worries about the person not managing their finances. In two cases in the telephone survey, for instance, these concerns were about possible financial abuse from relatives or 'friends', and the decision was about protection of the individual's financial interests. In Report 2, 3.1.2, for instance, an example is given of a man with learning disabilities who was being financially abused by his staff. In the interviews, two 'new' cases were followed up, both relating to older people where there were suspicions of financial abuse by relatives (see Report 3, 3.2 and also Appendix A for the case study on F12). Mistrust of others surrounding a person can therefore be a key safeguarding trigger, and can involve not only finance, but also other related aspects of safety. An example from the interviews is given in Report 3, Section 2.1:

A young woman had her financial decisions made for her by corporate appointees. However, these professionals also had concerns and overview over her mental health needs, and were often the first people to pick up any new problem that might be emerging. This was a young woman who came from a background where her stepfather was suspected of abuse, and so she was very vulnerable. The best interests process was sparked in this case when the woman wanted to take money out of her account to buy a second hand car. In addition to the concern about her using her money unwisely, the appointees suspected that she might have been 'used' to buy the car. In that case, however, their assessment of her capacity for that decision was overruled by a social worker, who said that she could essentially make that 'unwise decision' for herself. (F15, Report 3)

2.4 A change in social care needs

Closely linked with the above category of safeguarding was that of a change in social care needs. In the online survey, as seen above in Table 10, 35 of the 93 social care decisions (38%) concerned matters which did not involve 'adult safeguarding' nor a change in accommodation.

Some of these were specifically about personal care (N=5) or everyday issues (N=6), some were brought up through a care review (N=5) and 16 of them were classified as 'other'. In the telephone survey, likewise, there was a group of cases which appeared to have been precipitated at least partially by the noticing of a social care need, rather than a health care need (see Report 2, 3.1.3). Most typical in this group were those cases where a breakdown of existing care arrangements was foreseen:

The difficulty arose because his wife really didn't think she could cope. She didn't think her husband had capacity to weigh up the implications of him going home; he couldn't manage stairs, and the house had steps up to it [T12]

As noted above, many of these situations became apparent at the point when the person had a health intervention. However, five telephone interview cases were more closely intertwined with a refusal to accept care or support. As noted in Report 2, 3.1.1, one man refused to have his hair cut, and another woman was described who was unfit to go out in public due to the way she dressed. These situations only became matters for best interests decisions because of the person *disagreeing* with elements of their care plan. A case that is

discussed both in the telephone survey and then followed up in interviews is given here as an illustration of how best interests processes can be triggered by the need to enforce particular aspects of care:

An older woman with dementia was living in a care home, and was resisting the advice to change her underwear. The first thing the staff did was to try and persuade her to change, and then to respond to the problems caused by her refusals – she had become quite unpleasant to be with, and so she had to stay in a day room away from other residents. Since neither of these strategies worked, they had then to consider what to do next, and whether they could in fact carry out actions against the wishes of the resident herself. It was at that point that the care staff effectively carried out an informal assessment of her capacity, and had advice from their local MCA advisor about how to record that assessment. It was decided that she should be persuaded to change her clothes, if possible, without restraint, and she was encouraged to do so by the enticement of being present at a visit from the mayor. (T40 in Report 2; F13 in Report 3).

The links between social and personal care and health were apparent in this case. The lack of hygiene had not only led to this woman being very unpleasant to be with, but had also caused a glandular infection. Giving her the medication she needed then became a subsequent problem, possibly even greater than the first. As her staff team explained, 'It's just a vicious circle'.

In two cases, the best interests process was precipitated by a change in the person's actual care needs – in particular, escalations of challenging behavior amongst people with complex learning disabilities. However, no cases were described to us where a best interests process was put in motion by the need to assess or review someone's needs in relation to their overall care plan, and consent to accept a direct payment or personal budget was not mentioned at all. We can only conclude that those who were confident enough about their professional practice to volunteer for a telephone interview were using the Mental Capacity Act primarily because of situations which arose which were:

- Health related, or driven by a change in health status of the individual;
- Associated with risk, including immediate danger, to the individual or to others;
- Triggered by a need to look for a more protected living arrangement for individuals whose existing arrangements were no longer tenable.

3. Assessment of capacity

3.1 Good practice in assessing capacity

From the evidence of the online survey, a best interests decision was generally only made where someone had been assessed as lacking capacity. As seen in Table 11, the majority of respondents (321: 83.5%) thought that the person lacked the capacity to make the decision for themselves, and a further 28 (7%) were unsure. Further, the most common reason for deciding what was in the person's best interests was 'because the person lacked capacity to make the decision'. 271 (70%) of respondents chose that option, over the other possible ones relating to impairment, appearance or unwise decisions.

Table 12: The reason for deciding what was in the person's best interests (from online survey)

Reason	Number	Percent
Because the person lacked capacity to make the decision	271	70
Because of the person's disability, history, diagnosis or illness	67	17
Because the person was making a decision thought to be unwise	23	6
Because of the person's age, their appearance or their behaviour	13	3
Other	11	3
Total	385	100*

*The total does not equal 100% due to rounding

In the telephone survey and interviews, we were able to find out more detail about *how* capacity was assessed and *who* carried out that assessment. In the telephone survey, for instance, it was interesting that exactly half of the interviewees who were lead decision makers had also assessed the person's capacity (Section 3.2.1 of Report 2). Thus other professionals and people who knew the person well were often consulted and involved in capacity assessments, and the matter was clearly taken very seriously. Decision makers often deferred to others, who might either know the person better, or have more experience in decisions relating to a particular area of life. For instance, a consultant medical practitioner said that he would always ask the social worker for an opinion on capacity in cases relating to discharge, as social care needs related to social work, rather than medical expertise. As discussed in Report 2, there was a clear preference for consensus capacity assessment. As

one occupational therapist working in a geriatric hospital said:

Sometimes...occasionally I struggle in my own mind to work out whether somebody has got the capacity or not, but usually talking it through with somebody else we kind of reach a decision which makes sense. So having another – that's why it's good to have a few people there. [T13]

There was often an initial foray by a professional assessor, followed by consultation with others who were familiar with the person, and then repeated visits to ensure that an objective view of decision-specific capacity had been gained. Much of this could be described as team work, and with several assessors of capacity, the individual clearly had a better chance of proving that she or he *did* have capacity, or of having time to regain capacity, sometimes by being in a more relaxed or informal environment. While that could lead to disputes about capacity, nevertheless from the point of view of the individual, these disputes were often productive in allowing them the maximum chance to make a decision themselves.

The joint nature of capacity assessments was reinforced in the interviews. In only nine of the 25 cases did the same person take responsibility both for assessing capacity and for leading the decision. Some cases specifically favoured a multidisciplinary format, as noted in Section 3.2 of Report 3, and the communication between the different professionals involved in a capacity assessment was explored further as a theme. One of the points that arose from the interviews was that capacity assessment must involve more than simply listening to what someone says they want. On some occasions, interview participants mentioned that other professionals had wrongly assessed someone as having capacity, since they were able to speak up for themselves. For instance, that had happened with older people who said they wanted to go home, and also with a woman who had said she always wanted to be resuscitated. Clearly a 'joint' process of assessing capacity is not always about consensus, but also about healthy debate and differences of opinion, which cause professionals to stop and reflect about an individual's capacity.

However, some of the interviews also revealed a complex and more detailed picture of how conversations could be conducted with a patient or client, in order to get a fully rounded idea of their capacity. These are explored in detail in Case 12 in Appendix A of Report 3.

An older woman with some mental health issues was to be discharged from hospital, and the capacity assessment was described as a lengthy process over a period of time, particularly focusing on occasions on which the medical consultant and the social worker met with the patient and had conversations with her about her views. The social worker said: 'It's asking her what she feels, does she know where she is, does she understand what her needs are, how do you see yourself managing, you know; if the person's saying I want to go home, it's like, well how are you going to manage if you go home? Are there any risks, do you think, to you going home? Those are the sorts of questions we tend to ask. And then we wait for the response. And we might go off on different tangents depending on what response we get. So that's how generally she would have been involved in that process.' (F12b)

3.2 The concertina effect: assessment of capacity and best interests decisions

According to the Mental Capacity Act, a best interests decision is only to be made for those who lack capacity to make that particular decision, on that particular occasion (Mental Capacity Act 2005, c9, part 1 (2)). Therefore, in all our data collection instruments, the questions followed the logical expected steps, with assessment of capacity preceding a best interests decision. However, this theoretical clarity did not entirely concur with the real life situations represented in the data.

The first clues as to the timing of the capacity assessments come from the online survey. Table 13 below shows that the assessment of capacity was most frequently made on the same day as making the decision about a person's best interests (179; 49%), and this held true for all types of decisions.

Table 13: When the assessment of the person's capacity was made (from online survey)

Time when assessment of capacity was made	Number	Percent
On the same day as making a best interests decision	179	49
Up to a week previously	34	9
More than a week previously	95	26
Over the course of several weeks	29	8
Not known/not sure	28	8
Total	365	100

However, considering the different groups of people for whom best interests decisions were made, people with learning disabilities were significantly *less* likely to have an assessment of capacity made on the same day, and those with mental health problems were significantly *more* likely (Report 1, Tables 26 and 27). Unsurprisingly, the small number of people who were intoxicated or unconscious also tended to have their capacity assessed on the same day as the best interests decision, and this would relate no doubt to the urgency of taking action in those cases. Thus there seem to be frequent occasions on which an assessment of capacity occurred at virtually the same time as the best interests decision, thus concurring with the Code of Practice in ensuring that the person's capacity is assessed at a specific time for a particular decision.

In the telephone survey, we explored further the issue of timing of an assessment of capacity. Although most of the respondents (52 of 68) said that they had led the best interests process, only 26 had actually led the capacity assessment. Most of our interviewees also said that they had followed the Mental Capacity Act and the Code of Practice in carrying out assessments of capacity, and Report 2 (Section 3.2.3) outlines some of the different processes that were described. It appeared that there were many different ways in which an assessment of capacity fitted within a best interests process. In urgent cases, such as the six ambulance cases in the telephone survey, an assessment of capacity had to be carried out very swiftly, and four of the ambulance respondents said that they used a standard checklist based on the four key criteria in the MCA guidelines.

At the other end of the spectrum of capacity, there were clearly people in whom a lack of capacity was 'assumed'. Two interviewees said there had been no specific assessment of capacity, and a further three at least were unclear. These cases concerned people who had a known impairment, were difficult to communicate with, or who were well known to services. However, between these two extremes (of assumed incapacity and an urgent need to assess quickly), there were many lengthier processes undertaken, all broadly subsumed under the banner of consensus capacity assessments. These were all cases, described in Section 3.2.1 and 3.2.2 of Report 2, where those familiar with the person had been consulted, several visits had been made to the person, and sometimes a formal team process for the capacity assessment had been undertaken.

As noted in Report 2, even in urgent medical contexts, there was clearly a preference to discuss the assessment of capacity and to involve another person. Despite these lengthier

and thorough processes for assessing capacity, however, a theme emerged which we described as the 'concertina effect', since questions of capacity only seemed to be tackled in many cases alongside the decision itself. In many cases precipitated by risks posed to a person's wellbeing, the decision had already effectively been made. However, it was the assessment of a lack of capacity which then had to be agreed, in order to implement the decision. That relationship between lack of capacity and best interests decision became most clear when there was a dispute about the issue of capacity, and an example is mentioned in Section 3.2.1 of Report 2, which will be expanded here as an illustration.

An older man had been admitted to an acute hospital several times. He lived on his own at home, with some support coming in to give him drinks. However, his mobility was very limited. The discharge nurse felt that this man should not be living alone, and would be better off in a care home. She therefore found that the patient did not have capacity to make the decision about going back home, and that he did not understand his own physical health care needs. However, when the social worker became involved, she judged that the patient did have capacity to make his own decision, and suggested a compromise position where the man could receive slightly more day care in his own home. She also criticised the original capacity assessment, as having been badly documented. (T48 in telephone survey)

It can be seen here how the assessment is tightly linked to the decision which is already in the mind of the person leading the process of discharge. A 'lack of capacity' judgement is in effect a key to ensuring that the person is protected, and is particularly relevant when someone is disagreeing with a proposed course of action. The complexity of that linkage was pursued further in the interview stage (see Report 3, Section 3.1). For instance, a man in a psychiatric ward was described (F23) who was resisting personal care and hygiene routines. Staff members did not want to assume that he lacked capacity, and were hopeful that he would agree to care for himself, given time. However, there were conflicting pressures, due to his state of cleanliness and his health, and so effectively in the end the assessment of capacity had to be made at the same time as the best interests action, to ensure that he did get washed. Even in more formal accommodation moves, an assessment of capacity could be ignored until a conflict or difference of opinion emerged. In F08 (Report 3, Section 3.1) a man moving out of an NHS campus was only assessed as lacking capacity when the placement he had been found was disputed by those who knew him well. As noted in Report 3, the dilemma here is about the conflation of a lack of capacity with the enforcement of a

decision which has effectively already been made.

3.3 The basis for assessing capacity

The online survey, as mentioned above, revealed that 70% of respondents felt that the best interests decision they were describing was related to the person's lack of capacity to make the decision for themselves. However, as Table 12 above shows, other reasons also swayed some respondents, 17% of whom said that the decision was made because of the person's disability, history, diagnosis or illness. A further 6% said that it was made because the person was making an unwise decision, and 3% related the decision to the person's age, appearance or behaviour. It was noted also that over half of those decisions relating to disability or diagnosis were made by health care professionals, and the majority of those respondents thought that the person's interests were decided upon quite well or extremely well. These responses, however, do indicate some misunderstanding of the MCA in relation to why a best interests decision needs to be made, although they may also be indicative of the complexity of several of these cases.

A survey is, however, quite a crude instrument in attempting to understand what lay at the heart of an assessment that a person lacked capacity. In the subsequent stages of the research, we were able to explore these matters in more depth. About half of the telephone respondents explained that the person lacked capacity because of their inability to understand either the nature of the decision or the potential consequences of making it (Section 3.2.4 of Report 2). Typically, the discussion revolved around people who lacked the capacity to understand their own needs for care or support, and so were resistant to attempts to protect them from harm. As we noted in Report 2, there was certainly a blurred edge between these explanations of lack of capacity and the notion of 'unwise decisions'. An illustration is given here which is mentioned in 3.2.4 of Report 2:

A young man had had a spell as an in-patient in a hospital. However, he was due to be discharged. The matron of the ward described how his parents had questioned the man's capacity to manage his own affairs, when he moved back to his own flat. The fact that he was in the ward gave staff time to confer with each other, and to assess the man carefully, asking him questions about how he would live and what his priorities were. As the interviewee said, 'his priority would be to go and buy dog food instead of paying his rent. He couldn't understand the link between non-payment of rent and being evicted, and what

eviction would mean. He was unrealistic, he thought he'd just be moved into another flat somewhere. (T15 in telephone survey).

A further example is the man in T17 who had difficulty with friends who were drug dealers; he was said to be driven by his wish to have 'freedom without responsibility'. Underlying all these assessments was not just a cognitive lack of understanding, but a perceived lack of insight into one's own needs. At the interview stage, we were interested therefore in pursuing the question of assessment of capacity; this was not just about *how* capacity was assessed in terms of process, but also the basis of the assessment. How did people know when someone lacked capacity?

A key principle in the MCA is that there should be a presumption of capacity, unless someone is specifically shown to lack capacity to make a particular decision. However, with certain groups of people, this principle appeared to go unnoticed. In the interviews there was a clear distinction between people who could not communicate a decision, or perhaps did not even respond to another person's presence, compared with those whose capacity had to be more carefully considered and differentiated. About one third of the people described in the interviews fell into that former category, and it was really an assumption that their lack of understanding of verbal language, their lack of ability to communicate and their failure to grasp a serious decision was ample evidence of their lack of capacity. For instance, a man who was being assessed for a PEG tube procedure was seen as unresponsive, and almost unconscious, when visited by the specialist nurse. Similarly, people with profound learning disabilities were described as unable to communicate other than through their facial expressions or behaviour. In all these cases, it seemed that the impairment did dominate, and that practitioners had some difficulty in adhering to the principle of presumption of capacity.

With others who had lesser impairments, however, as is seen in Section 3.3 of Report 3, 'insight' played a key role. Participants admitted that they had to go by their gut feeling on occasions, but what they looked for primarily was evidence that someone had enough self-awareness to make a sensible decision.

For instance, in F04 an older woman wanted to 'go home' from hospital, but the solicitor involved with her case said explicitly that 'she hasn't got capacity to make that decision

because she lacks the insight'. . The word 'insight' is not included in the Code of Practice for the MCA, and is perhaps most frequently associated with mental health diagnosis. In common parlance, however, it appeared to be shorthand for saying that a person could not understand and weigh up the consequences of their own impairment or their own needs for support. As we noted in the interviews, participants tended to emphasise the complexity of cognitive skills needed by patients or clients. For instance, if someone had become physically ill, then their needs might have changed considerably. Not only did they have to acknowledge and understand this change in their circumstances, but they were often expected to think back to their home circumstances and to predict what it would now be like to live at home.

Many participants realised fully how difficult and complex an issue capacity was, and they frequently spoke about the efforts they had made to support the person's capacity, by giving prompts or hints to them. Sometimes these prompts were simply verbal, particularly with older people or those with dementia. In the case of people with learning disabilities, they were sometimes given more concrete experiences. In one case (F08) for instance, where there was a decision about a prospective move, a man moving out of an NHS facility was taken to see his prospective new home, and photographs were taken to remind him of each visit. However, he was still deemed unable to understand. All these prompts and support were mentioned by participants almost as a moral justification for their final assessment that, despite the help given, a person still did lack capacity for a specific decision.

3.4 Capacity as a blurred concept

In examining data at the three different stages of this research, we were interested not only in good practice examples, but also in the cases which apparently flouted the Mental Capacity Act Code of Practice. For instance, in the online survey, we found that 36 of the 385 respondents had indicated that a best interests decision was made for someone who *did* have capacity. That might have been a straightforward error in filling in the survey. However, ten respondents (4%) reported on two separate occasions that an assessment of capacity had not taken place (Report 1: Section 5). In the 36 cases where the person was said to have capacity, it was interesting to see that 28% (N=10) said that the best interests decision was made because the person was doing something 'unwise'. A further 47% (N=17) said that the best interests decision was made on the basis of 'the person's disability, history, diagnosis or illness'. These reasons for a best interests decision, which are not in

accordance with the MCA, accounted for 75% of the group of people who attributed capacity to the person for whom the decision was made; by contrast, only 15% of the 321 people who said the person lacked capacity said that they had based their best interests decision on this faulty reasoning. We concluded therefore that the reasons for this apparent lack of compliance with the Mental Capacity Act should be further explored in the telephone survey and the interviews.

As mentioned above, the basis of a mental capacity assessment was seldom a straightforward affair. Particularly with those whose capacity fluctuated, it was often hard to pick out exactly why the respondents had assessed the person as lacking capacity. In the telephone interviews, we explored how disagreements often brought to light the flaws in the process of assessing capacity (Report 2, 3.2.5). For instance, an older woman (T56) living in sheltered accommodation had showed signs of being unable to cope by herself. Following a fire she was admitted to a care home temporarily and the decision was whether her admission should be made permanent. A psychiatrist found that the lady did have capacity, but the social worker (who had spoken to us on the phone) felt that the psychiatrist had only seen the client briefly on a 'good day', and that she generally displayed a lack of awareness and an inability to care for herself. Clearly there are possible issues both in the psychiatrist's rather brief approach, and also in the assumption made by the social worker that an inability to care for oneself equates to a lack of decision making capacity. A common pattern in many of the cases, with older people in particular, was that inability to manage one's own independence and care were confused with inability to make a decision. The two became conflated, and so it was rare that an older person was assessed as lacking capacity, but able to live independently with support.

In the interview stage, we followed up this precise question with some of the participants who had described a similar case. We asked them specifically to think of any cases where a person was assessed as *lacking capacity* but had a best interests decision made which was in favour of their independent living. This question was asked in a solicitor's office, a geriatric hospital and a private care home, and in all cases, the participant had to think carefully to find single examples of such cases amongst older people and those with dementia. The presumption seemed to be that a lack of capacity meant the person needed more protection and support within a care home.

A further confounding factor, explored in Report 3 (Section 3.4), was the issue of 'personality' and how that could affect a capacity assessment. Participants described people who they felt *did* lack capacity, but who had strong personalities which belied their lack of understanding and insight. They felt that people like this who could speak up strongly for their own wishes could easily give the impression that they were in control, when in fact, they could be quite confused. For instance, that line of reasoning was applied to a woman who refused to care for her own hygiene (F13), the man in F09 who had unfortunate friendships with drug dealers, and even the woman who was dying of heart disease in a nursing home (F14). In this last case, the problem about capacity came about because of the woman's denial of her imminent death, and her refusal to consider how that death should be managed. The case will be outlined here as an illustration:

An older woman with heart disease had had spells in a private care home, but also kept up her own home, which she valued greatly. She lived alone and was an intensely proud and private person, described as quite strong-willed and eccentric in her lifestyle. She was told by a GP that she had only 2-3 months to live, and she said to him that she would always want resuscitation. The GP therefore said that she should always be resuscitated. However, when she finally had to come back to the care home for her last weeks of life, the staff there were very unhappy at the thought of resuscitating her, since they knew that the likely consequences of that would be that she would have a difficult death in hospital. They felt that she lacked capacity to make that decision for herself, since she was in denial about her imminent death. In the end, it was found that a nephew of hers had a valid LPA, and he wrote a letter endorsing the decision not to resuscitate her. This swayed the GP, and in the end she died a peaceful and natural death. (F14 in Report 2).

In the end, our participants (a palliative care nurse and the home manager) agreed with each other that this type of decision should not depend on an assessment of capacity, but should be entirely a medical decision, based on the likely outcomes and health of the individual patient.

If capacity can be over-estimated in cases where a person has a strong personality, then of course it can also be underestimated in those who do not speak up for themselves. Many of our participants were aware of these dilemmas, and felt keenly the responsibility of making an assessment that someone lacks capacity, which often conflicts with the deeply-felt duty to

support autonomy, as a corporate appointee commented: *When people are borderline as to whether they lack capacity or not, it's a bit invasive of that person's rights (F16)*

As discussed in Section 3.3 of Report 3, one of the solutions to this dilemma was found in the understanding of capacity as being decision specific. However, the blurred edges of capacity assessment remained the largest problem for many participants at all stages of the research. In the spirit of the MCA, one interview participant said that 'capacity is not an all or nothing concept'. A psychologist (T12) commented that the four points in the guidance make it sound easy, but that belies the complexity in real life. While some respondents at the telephone stage in particular talked through the way this complexity could be handled, and related it strongly to the need for further staff development, others were still aware of the ongoing problems in assessing capacity. Unwise decisions and other matters which confuse the concept of capacity should perhaps be dealt with in the Code of Practice in greater detail than at present. A solicitor summed up neatly the issues discussed in this section:

I don't think it's a problem with the best interest decision. I think the difficulty is the concept of whether somebody's got capacity or not. And that is it. And on a decision-specific basis, everything's going to hinge on whether they've got capacity. And the problem is that you go back to section 1: if somebody's got capacity, just because they make an unwise decision, it isn't a decision that they can't make. So you could have somebody that I'm saying, "well they clearly haven't got capacity", and somebody else is saying, "Oh no, they just want to be silly. Well that's up to them, that's their prerogative". (T12: Solicitor in telephone survey)

4. Making a best interests decision

4.1 When does the best interests decision happen?

We have explored above, in Section 3.2, how an assessment of capacity was often in reality interwoven with a best interests decision, both in terms of the timeline of the process and in terms of the argumentative links between *lacking capacity* and *having to accept* a best interests decision. Another question in the online survey related to the time taken to actually carry out the best interests process as a whole. Table 14 below shows that the sample of 385 responses were split almost equally between three broad categories, those which took place in one day (urgent decisions), up to a couple of weeks (semi-urgent) and over a course of several weeks (non-urgent). Table 14 looks at those categories in relation to the different types of decision.

Table 14: The time taken to determine the person’s best interests in relation to the type of decision that needed to be made (from online survey)

Time scale	Healthcare matters (%)	Personal welfare or social matters (%)	Property or financial affairs matters (%)	More than one matter (%)
Up 24 hours	38	31	22	26
Up to a couple of weeks	29	32	28	33
Several weeks	33	37	50	41
Total %	100	100	100	100
Total number	184	93	8	78

Although not statistically significant, it seems that urgent decisions were more likely to fall into the health care category, and lengthier decisions were more likely to be about property and affairs, or about more than one matter. Unsurprisingly, further analysis showed that urgent decisions were most likely to be associated with people who were unconscious or who were under the influence of drink or drugs.

Section 8 in Report 1 goes on to investigate cases where a decision could have been delayed, and whether in fact it was. Tables 33-4 in Report 1 indicate that almost half of respondents thought it impossible to delay the decision, particularly in health care or personal welfare matters. The possibility of delaying a decision was not statistically linked to any particular impairment group, but where there had been disagreement about the person’s

best interests, it was significantly more likely that the decision had been made over a series of meetings and it was less likely to have been made within 24 hours.

It is interesting therefore to examine further the extent to which certain decisions could perhaps have been made in a more leisurely and considered way, rather than be rushed through in 24 hours. The 'concertina effect' of capacity assessment and best interests decision was much more likely to happen within the urgent decisions, and the telephone survey and interviews allowed us to examine cases in which urgency was resisted, in order to allow someone to regain capacity, or to involve more considered opinions. Delay can be construed both as a positive and a negative, however, and we also heard of cases where delay was detrimental to a successful outcome.

Taking first the cases where delay appeared beneficial, six telephone interviewees specifically discussed the reasons for a more protracted process in making a best interests decision. In T04, a solicitor was discussing the case of her father who had been brain injured, and she referred back to the original decision for him to move into a care home, saying that this had been delayed for some 18 months, as 'the whole idea was to see if he could be rehabilitated'. That was clearly appropriate where a life-changing decision about moving out of one's own home was at stake. A consultant psychiatrist in T21 described a case about medical treatment for a woman with learning disabilities, where 'it was one of those cases where a decision did not have to be rushed'. In his view, the delay enabled people to go away and get more information about the operation at stake, and the potential consequences of it for the woman. Other respondents also talked about the value of not putting pressure on a person, especially in situations relating to a change of accommodation, and finally one case in particular was delayed specifically in order to ensure family relationships were not unduly damaged. That case will serve as illustration here of how timing can be crucial in a best interests process:

A young woman with moderate learning disabilities was living with her parents, who had some issues of their own. Her mother had early onset dementia, but nevertheless, their relationship was very close. The problem arose when the woman developed some mental health difficulties, and the psychologist involved felt that she needed to leave the family home for a short period, to have mental health interventions. The family was very much

against this suggestion, and the daughter sometimes said she wanted help, and sometimes went with her parents.

Because of the complexity (and whole family's interests being involved), this took a long while to resolve. It wasn't until the daughter started to do clearly dangerous things (going out at night) that her parents agreed she was a risk. In terms of outcome, the young woman did in fact go and have a period of treatment, and then went back home with a support package, meaning that she does now go out, and she has links outside the family home. Nevertheless, the relationship between the daughter and her parents was maintained. (T26, Report 2)

Delays however were not universally seen as beneficial. Much depended on the reason for the delay, and in some cases bureaucratic muddle, uncertainty or lack of decisiveness contributed to a delayed outcome which was sometimes not in the person's best interests. We have seen above that disagreements were more likely to lengthen the process of decision making, and we will explore further below the preference for 'joint' decision making. All these trends could result in a lack of decisiveness, which was a problem in a few cases. For instance in Report 3 (Section 4.5), a case is mentioned in which an older man wanted to return home to his wife, following a spell in hospital, but there was some disagreement between social workers, IMCA, family and solicitors about the best outcome, since the wife was not well herself and could not cope with his care. During the time it took to sort out this case, the man himself was living in a care home which he disliked intensely because of the noise and lack of privacy, and his wife was also becoming more and more distressed. That case was resolved eventually by the family being supported to choose a different care home, and so the outcome was successful.

However, in other cases, delays had taken so long that they endangered the health of the person lacking capacity. In F11, for instance, a man waiting for a PEG tube operation had to wait for all parties to agree on his best interests, including a consultant, a specialist nurse, care home staff and an IMCA. Because of difficulties in exchanging reports and bringing together all points of view, his health had deteriorated again at the point when he could have had the operation. That meant a further delay, which could have proved fatal. Fortunately, he did in fact have his operation successfully in the end.

In Appendix A to Report 3, the case of 'Lily' is explored in depth. She was an older woman living in hospital, who was awaiting discharge to a care home. However, there were complex issues about her finances to be sorted out, and so the best interests decision effectively fell into the 'more than one issue' category. A careful and very person-centred process was followed, but in the end, Lily died before she could move out of hospital. Although this was described as both upsetting and frustrating, the social worker involved said that she thought that might have been the best outcome. Lily had adapted and got to know the people in hospital, and so was more comfortable and secure in spending her last days there than she would have been in a care home. However much planning is put into decisions, life and death have a tendency to take over.

4.2 Who leads the best interests process?

It was not surprising that health care decisions reported in the online survey, and decisions involving more than one matter, involved a majority of health care professionals. However, social welfare decisions, and those about property or financial affairs involved health care professionals almost as frequently as social care professionals. That odd finding may well be because of the relatively large category of decisions involving discharge from hospital, as seen above in Section 2.2, in which health care professionals would have been involved. It may also be because a large number of our respondents identifying as health care professionals were not actually clinicians, as shown in Table 15 below. They included 59 nurses, 88 professionals allied to medicine, 30 people working in Mental Health, and 19 in long stay hospitals or NHS care homes. It should be remembered, therefore, that 'Health' is a very broad field.

Table 15: Professional groups of respondents in online survey

Professional role	Number	Percent
Health clinician	48	12.5
Nursing	59	15.3
PAMS (Professions allied to medicine)	66	17.1
Staff in long-stay hospitals or care	19	4.9
Residential homes	43	11.2
Social care practitioners	54	14.0
Legal practitioners	4	1.0
Mental health professionals	30	7.8
Psychologists	12	3.1
Ambulance staff	26	6.8
Family/friends	7	1.8
IMCA	7	1.8
Other/not given	10	2.6
TOTAL	385	100

The online survey revealed that almost half of respondents were part of a multi-disciplinary team making a best interests decision, and a third were joint decision makers; only a small proportion (7%: 26) claimed to be the sole decision maker (See Figure 3 in Report 1). Further, Tables 7 and 8 in Report 1 revealed that health care matters were significantly more likely to be resolved within a multi-disciplinary team than other types of decision. Breaking down these figures yet further, the different professional roles within health care also seemed to matter. The greatest trend towards multi-disciplinary decision making appeared to be reported by nurses, of whom 56% were part of a multi-disciplinary team and by professions allied to medicine, of whom 61% were part of a team.

Similarly, those involved in personal welfare decisions were also most likely to identify as part of a team or as a joint decision maker. Social care practitioners (e.g. care managers) were most likely to describe themselves as joint decision makers (46%) while residential home staff for example were most likely to be part of a multi-disciplinary team. The numbers who fell into these categories were small. Nevertheless it is worth noting that 12 of the 31 residential home staff answering the survey said that they were not involved in making the decision.

From the online survey, then, we started to get a clear picture of the preference for joint and/or multi-disciplinary decision making, which we felt was worth exploring further. In the telephone survey (see Report 2, Section 3.3.1), one of the first points that struck us was the reluctance of interviewees to identify as having 'made a decision'. In answer to an opening

gambit of 'Were you the decision maker?', people tended to shy away and answer as this mental health professional did:

All the ones I've been involved with are very much a team effort. It's not one person making a decision. (T 31)

The burden of responsibility for making a decision was something mentioned frequently by our interviewees. Consensus was preferable by far to sole decision making. Even paramedics tried to act jointly with others on the scene, during urgent life-threatening situations, and one spoke of feeling a 'significant burden' if that support was not there.

In the telephone survey, however, we also noted the importance of someone actually taking responsibility. In some cases, the confusion about who was the decision maker could be crucial, and in Section 3.3.1 of Report 2, we explored the difficulties encountered by a man with learning disabilities and challenging behaviour (T49), who had developed some disturbing additional problems. A best interests process had been carried out involving care home staff and also his care manager, and it was agreed that blood tests should be undertaken, in order to look at possible physical causes of his behaviour. Carrying out those blood tests was difficult, and entailed sedating the man; however, while all this was being discussed, the consultant then decided unilaterally that the blood test was unnecessary. However, the interviewee argued that perhaps the consultant did not have that right, since it was the phlebotomist who would actually carry out the blood test, and that should be considered separately. Clearly, these matters needed both clarity and coordination.

During the interview stage, we were able further to distinguish the different aspects of what it means to be a 'decision maker', and in Section 4.3 of Report 3 we explored for instance the different patterns of implementation for straightforward medical or nursing cases on the one hand, and more complex multi-agency cases on the other. What also became clear was the distinction between a) actually taking responsibility for the decision and b) leading the best interests process. Those two functions were not necessarily always carried out by the same person. In F24, for instance, it was the senior safeguarding nurse who both coordinated the process and advised other staff, in a decision about medical treatment. However, it was the consultant who made the decision. The example will be given here to illustrate how these different roles can interrelate effectively:

An older woman had a history of psychosis, and had lived for the past 3 months in a care home. Due to behavioural problems, she had then been admitted on a voluntary basis to a mental health unit. Following the onset of shortness of breath, she was relocated to a medical unit, where she was diagnosed with pleural effusion. There were also underlying fears that she may have cancer. Doctors wanted to implement a medical intervention to treat these problems, via the insertion of a chest drain. However, while consenting to some medical investigations, the woman refused all offers of treatment, saying that God would make her better. Due to her refusal of treatment and doubts about her mental capacity, the consultant liaised with the hospital's Mental Capacity Advisory team on the best course of action. The safeguarding nurse who participated in an interview for this study said that 'My role is really making sure that everybody's complying with the Act'. (F24, Report 3)

Leading a best interests process, then, was defined variously in terms of providing expertise about the Mental Capacity Act, ensuring that all relevant parties were involved, organising any meetings that needed to happen, and making sure that other professionals understood and played their role adequately. Part of that role could involve chairing a meeting, although not all decisions were made through meetings. The particular issues to do with meetings are explored below in Section 4.3.

Making a best interests decision, by contrast, was specifically about being the person who took responsibility for deciding on the best course of action. That role involved being able to weigh up the different factors discussed in any forum, and also sharing specialist knowledge with others. Although decision makers all preferred the idea of a consensus decision, nevertheless there were situations where they in the end needed to be bold enough to take on that responsibility. The Code of Practice as it stands does not perhaps sufficiently deal with these issues about joint decision making, and the necessity for responsibility in certain cases. Further discussion or clarification could be helpful.

4.3 Formal processes under the MCA

The Mental Capacity Act offers some formal structures which should assist with best interests decisions, including the ability to make a lasting power of attorney, or to have a corporate deputy managing the affairs of a person lacking capacity. Advance decisions to refuse treatment are also a formal part of the Act. However, scant reference was made to

any of these features of the Act in our data, and so a general conclusion could be that they are under-used.

A decision was made by our Advisory Group early in the research that we should not specifically seek to include lay people who had an LPA. In the online survey, four respondents were Court Appointed Deputies, and one had a Lasting Power of Attorney (LPA) for Property and Affairs. These five respondents were involved in the decision-making process to varying degrees: of the 4 Court Appointed Deputies, 1 was the sole decision-maker and 2 were part of a multi-disciplinary team that made the decision. The fourth reported that they were consulted but not involved in the decision-making process. The respondent who had a LPA for Property and Affairs reported that they were a joint decision-maker.

In the telephone survey, three cases related to decisions for someone to have their financial affairs managed by a financial attorney, or a corporate deputy (T5, T9 and T46). In one area, the appointees unit in the local council managed the finances of a wide range of clients, and made smaller decisions on a regular basis if someone wanted to withdraw over their agreed limit. The trigger for taking over the financial affairs of an older person was often the mistrust of relatives or friends who may have been abusing their relative's confidence (for example in T46). In those cases, the ability to have power of attorney for financial matters appeared to work very well. These were all situations in which the person lacking capacity did not in fact have control over their finances in any case, since relatives had been doing that previously. Therefore, the outcome was successful, in that the person had their finances safely managed, by a trustworthy person. In one case, this was a friend, but in the two other cases, it was a member of the care home staff.

Support for lay deputies or LPAs was occasionally brought up in our interviews, as a vital matter. One man, for instance, had previously had a 'receivership' order for his mother's affairs (T36), but understood that this would now change with the MCA. However, his interactions with the Office of the Public Guardian were very muddled, and he felt that this had delayed matters with his mother's accommodation arrangements.

Finally, one of the cases in the interviews particularly dealt with the matter of advance directives, as well as LPAs (F14). In that case, described in Section 3.4 of this report, the

patient was an older woman who had a terminal illness. She did not have an advance decision to refuse treatment, and in fact had deliberately asked not to have one put in place. Unfortunately, that was mis-represented by her GP as a decision and a right to have life-sustaining treatment under all circumstances, and it was that problem which triggered the best interests process led by her care team. In the end, it was discovered that this woman had a nephew who had a lasting power of attorney for her, and his intervention swayed the process for her, by persuading the medical practitioner towards a decision to allow her to die a natural death. Although this was only one instance, in the opinion of our interviewees the case clearly illustrated the efficacy of the LPA arrangement.

4.4 How best interests processes were structured

One of the early findings we noticed in the online survey data regarded the process of decision making. As shown in Table 16, over half of all decisions regarding personal welfare or social matters, property or financial matters, and more than one matter, involved a series of meetings between the decision-maker, the person and usually others who knew the person. However, this was the case for only 31% of healthcare decisions. Healthcare decisions were significantly more likely than other types of decisions to be made at a single meeting, or at meeting(s) that did not involve the person lacking capacity.

Table 16: The process of decision-making in different contexts (from online survey)

Process of decision-making	Healthcare matters (%)	Personal welfare or social matters(%)	Property or financial affairs matters (%)	More than one matter (%)	N
A series of meetings involving the person, the decision-maker and others who knew the person	24.5	42	39	58	N=140
A single meeting involving the person, the decision-maker and others who knew the person	26	21.5	21	6.5	N=80
A series of meetings between the decision maker(s) and the person lacking capacity	6.5	10	14	5	N=29
A single meeting between the decision maker(s) and the person lacking capacity	16	11	11	11.5	N=53
A meeting or series of meetings that did not involve the person	17.5	7.5	4	8	N=46
Other	9	5	7	10	N=31
Not sure	0.5	3	4	1	N=6
Total number	184	93	8	78	N=385

In subsequent stages of the research we were able to explore more precisely what that finding implied, and several more refined models were found to operate in different contexts. For instance, a single meeting could be simply the 'icing on the cake' and a way of bringing together a whole string of prior work in consultation and preparation. Alternatively, a single meeting could imply that the process was urgent, and that not everyone was properly informed or prepared. Similarly, those processes involving a series of meetings could be differently shaped if they took place within regular multi-disciplinary team meetings, as compared with special meetings called in order to bring together people relevant to a particular case. There were many different combinations of these models in the data, but an attempt will be made here to outline some of the 'patterns' that frame these different processes, and the ways in which they can be most helpfully applied. Although they are presented separately, it should be assumed that elements of all these processes could and were selected, in order to provide the best context for reaching a best interests decision in any particular instance.

4.4.1 Urgent consultation or meeting

As seen above in Table 16, health care decisions were more likely to take place in a single meeting, and it can be assumed that at least some of these were urgent decisions about medical treatments that had to be made quickly. For instance, F24, which is given as an illustration in Section 4.2 above, was a case where there was a degree of medical urgency, and so parties to the decision had to assemble and reach a conclusion fairly swiftly, so that the woman's health problems could be investigated. Other examples of urgent situations were explored in the telephone survey, which closely matched the pattern in the online survey. Eleven of the 15 decisions which were carried out in two hours or under were health related, as seen in Table 17.

Table 17: Time taken for best interests process: telephone survey cases.

	Health	Social & welfare	Property & affairs	Other	Mixed or multiple	Total
2 hours or under	11	3		1		15
Up to 1 day		2				2
Up to 1 week	0	6			3	9
1 week- 1 month	1	8	3		1	13
1 month or longer	7	10	4	1	1	23
Not clear	1	4		1		6
Total	20	33	7	3	5	68

Urgency was also a feature, naturally, of best interests decisions taken by ambulance staff, and was also mentioned in a care decision involving restraint. Naturally, DOLS applications produced a situation in which the best interests decision has to be made quickly, within a prescribed period of time, and those situations are discussed separately in **Section 4.4.5**.

Even in urgent decisions, interviewees in the telephone survey described how they had managed to include and consult with others. This was not done through a formal meeting, but simply by talking with people who may have been present at the time. This happened for instance in several of the ambulance cases. In T20 where a man had taken an overdose, the paramedic was able to talk with the man's son, to ask for his view of what should happen, before taking the man to hospital. Similarly, in the intensive care unit, a discussion was held around the bedside of a woman with learning disabilities, in order to determine the possible outcomes of treating her chest infection with medication (T44).

What helped in urgent situations was that the person leading the decision was well informed, prepared in a general sense to know how to handle best interests processes, and identified clearly as the person taking responsibility for the decision. Paramedics in particular said that the Mental Capacity Act had helped them to take on that responsibility, without having to delay by contacting a doctor. An example is given here from the telephone survey to illustrate this category:

An emergency ambulance call was made in relation to a young man who was drunk and unconscious and unresponsive outside a pub and the decision was whether to take him to hospital. The ambulance crew who found the young man felt that he was probably just drunk, but felt nevertheless that it would be unsafe to leave him unattended and unconscious in the street. In that area, the ambulance service staff had all had introductory training, and were in a Trust where staff support each other about issues of capacity. The paramedic therefore had a checklist to assess capacity, relating to the four key criteria, and kept this on a card. He talked to the man's friends in the street, and particularly to the person who had found him unconscious, to determine if there was likely to be any complicating factors which could affect capacity. They all agreed that it would be safest for the man to be taken into hospital, and that is what happened. (T60, Report 2).

4.4.2 Single meetings with preparation

Turning to slightly less urgent cases, as seen in Table 16, meetings were generally preferred in the online survey. The value of a meeting was discussed by many participants, both in the telephone survey and in the interviews. As explored in Section 3.3.2 of Report 2, a meeting set up specifically around one particular case could be person-centred, and include people who had a personal involvement with the individual. For instance, in T01, which was a case concerning a change of accommodation for a woman with dementia, the IMCA involved in the case described how valuable it was to get people round the table. That included a senior person from social care as well as the care manager, a consultant psycho-geriatrician, a community psychiatric nurse, a district nurse, the IMCA herself and also a carer's representative who spoke for the woman's brother. We will explore further in Section 5 below how these different parties to a decision can best be involved. However, it became apparent in this particular case that the success of the meeting depended strongly on the preparation and information gathering that had gone on beforehand. Therefore, the key features of this model seem to be careful preparation, both in terms of contacting the relevant people, organising the meeting and also fact-finding. An outline of this case is given as an illustration.

An older man in the later stages of dementia lived with his daughter. He had been in and out of hospital a couple of times, but on this particular occasion he was in a nursing home on a 'respite' basis, and the decision needed to be made about whether he should move back home with his daughter. Both a psychiatrist and a social worker had assessed that this man lacked capacity, and the problem which had started the whole process was that he slept in

the same bed with his daughter at home. It was felt that this might be inappropriate, since he may not know this was his daughter any more. However, the IMCA got to know the man quite swiftly, and determined that he was fully aware that his daughter was a family member, and nothing else. At the meeting, she advocated that the man should go back home, and other parties at the meeting were able to arrange for better support to be offered to him. That is in fact what happened. (T01, Report 2)

Where preparation had not taken place, single meetings could be difficult, as has been described in F04 in the interviews (Section 4.1 in Report 3). The problem there, according to our participant, was that no-one was coordinating the process, and the social worker who came along to chair the meeting was not the same as the original social worker in the case.

Single meetings of course were also typical of quite urgent decisions, including those about medical treatment and consent. Like the 'urgent' category above, these required particular skills and confidence in the person leading the process, since it might often be the case that not everyone was contacted who could have been. Nevertheless, sometimes a decision had to be taken, recorded and carried out in a short period of time. That was so, for example, in the case of T28, where a man was dying of renal failure. Because of the short lifespan left to this man, it was not considered appropriate to spend that time entirely on meetings. It was more productive to enable him to do the things he wanted during his last few weeks, and to support him to die with dignity. However, it proved important then to ensure that things were properly recorded, so that future views and opinions could be incorporated at a later date, with transparency about the process that had actually been followed.

4.4.3 Multi-disciplinary meetings within a team

As seen in the online survey (see Table 16), a typical feature of best interests processes concerning personal welfare was the multi-disciplinary model. Decisions were often taken over a period of time, and there may have been a string of meetings. Further, over half of the respondents in the online survey identified that they were part of a multi-disciplinary team making a decision.

In the telephone survey and interview stages, we found that a particularly useful model was that of the regular meeting structure within a multi-disciplinary team. For instance, we followed that up in detail in Appendix A of Report 3, in Lily's story, and it also featured in both

the cases relating to operations to insert a PEG tube. We found also in Section 4.1 of Report 3 that a best interests process could be discussed under the umbrella of a meeting called for a different purpose, for instance within a care planning approach meeting in F25, or of course in discharge meetings in hospital (F21), and in F09 within a safeguarding meeting. In all these cases, it proved possible to address the best interests of a patient or client within a formal meeting that was not termed a 'best interests' meeting. Respondents found that this worked well, and was not problematic.

A regular multi-disciplinary meeting structure in a particular setting had the advantage that best interests would not be overlooked, and was a way to ensure that both everyday and more serious matters could be mulled over, so that any specific decisions could at least be identified. That was so in the illustration given below. What mattered here was that there were ways of feeding in the particular issues for a client into the team meeting, with opportunities to return to the client themselves, to involve family members, and to discuss things informally as well as formally.

An older woman with dementia was a patient in a small community hospital, and faced a discharge decision about whether or not she should go back to her own home or go into a care home of some type. She herself was judged not to have insight, since she did not recognise the level of needs she had. However, there was some confusion about whether or not this woman had made her wishes known in advance, about going home. Now she appeared frightened and confused. The process of a best-interests decision took place through the multi-disciplinary meetings held in the hospital. The interviewee, who was an occupational therapist, saw herself as 'bringing the BI process together', instructing an IMCA, and filling in the paperwork. However, her role was also to ensure that the woman's views had been taken into account, that her capacity had been properly assessed, and also that any relatives she had were consulted. All those activities took place outside the meeting, but were able to be reported back and discussed with colleagues. (F06, Report 3)

In other cases, where a multi-disciplinary approach was undertaken, it was seen how the meeting structure and formal minutes of a meeting, could be a useful way to ensure that actions were undertaken and 'work streams' set up, which would then inform future meetings. For instance, in F09 (see Appendix A, Report 3: Derek's story), more than one multi-disciplinary safeguarding meeting was held, with a social worker, safeguarding officer,

psychologist and home care manager. These meetings then set in motion the work necessary to explore alternative living accommodation for the man in question, to work with him and counsel him to see if he could understand the risks posed by his behaviour, and to advise the support staff team in ways of supporting him more effectively. Essentially, this all appeared to be good, sound practice in care management, which then morphed into a best interests decision at the point when nothing further could be done to ensure Derek's safety.

Despite this example, the data in BIDS in general indicated that care planning and reviews were not well informed by best interests processes. Therefore, this model of regular incorporation of best interests matters into care review meetings (including the 'care planning approach' in Mental Health) would seem to be a useful recommendation.

4.4.4 Special meetings set up for a particular case

As seen above, the models outlined here were not to be seen as discrete patterns. For instance, a special meeting for a particular case could be called within the format of a series of multi-disciplinary meetings, and that is in effect what happened in both the case studies in Appendix A, Report 3. The reason to set up 'best interests' meetings varied in different cases. It appeared that the forum for actually reaching a decision was often a smaller meeting, between key professionals involved in a case, while a larger, more person-centred meeting would then follow on from that. That happened, seemingly with success, in F12 (Lily's story in Appendix A) where the IMCA helped to persuade Lily's relative that the outcome would be a good one for Lily. In other cases, as explored in Section 4.1 of Report 3, the special best interests meeting had the opposite function. Instead of having already made a decision and then calling a meeting to explain that to relatives or close staff, in one case in particular (F01), meetings held at the client's home were instrumental in feeding back into the multi-disciplinary team meeting, and the final decision was a medical one which was taken by a senior medical practitioner, who was able to have an overview of everyone's opinions and points. This case is outlined here as an illustration. It has already been mentioned in Section 2.1 of this report, as an example of how and when best interests processes are triggered in medical treatment situations.

This was a decision about serious medical treatment, a PEG tube insertion for feeding, for a man with profound learning disabilities. The best interests process included a meeting where all the relevant parties met (GP, gastroenterologist, parents, home care staff) and everyone

agreed it was in his best interests not to have the operation. The nurse explained that there was a high risk of death during the procedure of inserting a PEG tube, so it was really a matter of balancing up two risks (death through eating; death through surgery). From the home manager's point of view, this meeting also gave her (the home manager) some additional medical information– i.e. that the operation was not necessarily going to stop the risk of aspiration. She was also very impressed that the consultant had bothered to get all the medical records, and there were good medical reasons for not performing the operation in the end. From the nurse's account, the outcomes of that meeting were then relayed back to the artificial feeding consultant, who was the final decision maker. As far as she was aware, he would have relayed this decision 'man to man' to the original consultant who had expressed concerns. It should be noted that the father of this young man was adamant that his son was not going to have the operation. There wasn't a conflict in this case, but the interviewee said it would have been very hard if others had disagreed with the parents. (F01, Report 3)

A special best interests meeting for a patient or client could therefore take many different shapes. In the case above, it was literally a way of bringing together people who had a stake in the decision, and allowing them both to be better informed, but also to express their own view. In other cases, however, it appeared to be important that the decision had already been reached outside that forum, since otherwise a meeting could be both distressing and inconclusive.

In all these processes, however, what was really appreciated was good preparation and information to inform the discussion. Again, as in other models, clarity about who was the decision maker was also appreciated, and the care home manager in the case illustrated above described the process like this:

There was a build up of getting to the point where we were going to the consultant with everybody having built up information about pros and cons and everything. And then when we got to that final one with everybody together, it was sort of, right, on this date a decision will be made, with the consultant having the overriding, 'we'll do it, or we won't'. (F01a)

4.4.5 Deprivation of liberty safeguards

As the study was not specifically about the deprivation of liberty safeguards, the researchers did not explore in any detail whether DOLS procedures were followed as required (since the focus was on best interests processes more generally). As the researchers were only able to highlight where there was *potentially* a lack of awareness or a lack of compliance with the safeguards, the DOLS findings should be interpreted with caution. Of course, more in-depth research into this area would be needed to draw more substantive conclusions – accordingly, a separate study by the University of Bristol (also commissioned by the Department of Health) is currently exploring this topic in more detail.

The Deprivation of Liberty Safeguards (DOLS) apply to people lacking capacity who are likely to be deprived of their liberty for the purpose of being given care or treatment in a care home or hospital. These safeguards are intended to protect the liberty of people lacking capacity who are living in institutions (Ministry of Justice - MOJ, 2008). Except in urgent cases, formal authorisation must be obtained before depriving a resident of liberty (Amended MCA - Schedule A1: Part 1). The deprivation of liberty must be in the individual's best interests, necessary to prevent harm to her/him, a proportionate response to that harm and where a less restrictive alternative is not available (MOJ, 2008).

Although a health or social care institution (such as a care home) may itself issue an urgent authorization of deprivation of liberty for up to seven days (Schedule A1: parts 4 and 5), an application for a standard authorisation must then be made to the supervisory body (such as the local authority). It is the responsibility of the supervisory body to initiate an assessment process to determine if it is in the resident's best interests to be deprived of liberty (part 4: section 33). However, as the Code of Practice for the Deprivation of Liberty Safeguards does not provide a definitive definition of what constitutes deprivation of liberty, whether there is a deprivation, rather than a *restriction* of, liberty will depend on the particular circumstances of the case (MOJ 2008, pp. 16–17). Accordingly, the Code of Practice states that health and social care professionals have a responsibility to identify “whether deprivation of liberty is or may be necessary in a particular case” (MOJ, 2008: Section 3.6). In addition, the following factors must be taken into account when deciding whether a resident is being deprived of liberty: (1) the effects of any restrictions or restraints on the individual; (2) any objections made by the resident or her/his family; (3) the availability of less restrictive options; and (4) the cumulative effect of all the restrictions (MOJ 2008, para 2.6; Boyle, 2009). Of course,

whether applications for authorisation of deprivation of liberty are made where necessary depends on staff awareness of the safeguards and the factors which contribute to a deprivation of liberty, *and* a readiness to recognise when a person may be deprived of their liberty. The researchers were not able to explore issues relating to the DOLS in-depth (particularly in relation to the online cases). Nonetheless, there did appear to be some variation in practice in relation to when authorisations for deprivation of liberty were being sought (and when related DOLS assessments were undertaken), particularly in relation to safeguarding cases.

The online survey showed that DOLS assessments appeared to have been undertaken as necessary when decisions about physical healthcare or serious psychiatric treatment were made about people lacking capacity who lived in a care home or hospital. Whilst over a third of the online cases relating to a move to or from a care home involved DOLS assessments, it was not possible to determine if DOLS assessments would have been required in some of the other care home cases. The types of restrictions applied following DOLS authorizations varied depending on the nature of the decision. Whereas care home moves involved restrictions relating to where the clients lived and their contact with others, safeguarding and healthcare decisions were somewhat more constraining, involving restrictions on where clients lived and/or staff using physical means to control their movements or the use of medication. In addition, of course, DOLS authorizations in health care cases sometimes resulted in staff exerting control over treatment. It was unclear whether DOLS assessments should have been undertaken in around half of the adult safeguarding cases in the telephone survey (13/24) where restrictions had been applied to these clients. It may be that safeguarding is an area where compliance with the Deprivation of Liberty Safeguards could be improved, but more in-depth research into safeguarding practice would be necessary to determine this.

Eight cases were explored in more depth in the interviews, where DOLS applications had been made (or alternatively may have been necessary) relating to clients with dementia or a learning disability. Five of the cases related to detention in care homes and three related to the use of restraint (chemical and/or physical). Whilst DOLS processes necessarily involve best interests assessments, alternatively, a best interests process can highlight restrictions on clients' freedom which then trigger a DOLS process. However, some professionals appeared to lack awareness of the deprivation of liberty safeguards as they initiated best

interests and/or safeguarding processes when perhaps DOLS procedures should have been used. Alternatively, in one instance, it appeared that the Mental Health Act should have been applied instead. In five out of the eight cases, the assessment of capacity had been problematic (either because capacity had not been clearly determined or the assessment was repeated when it was initially inconclusive). As five cases involved the use of detention and/or restraint but DOLS authorizations had not been sought, it appeared that some professionals may have lacked understanding of when restricting the liberty of a person lacking capacity can constitute a deprivation of liberty.

In turn, it appeared that DOLS assessments may have been necessary in certain instances to confirm whether a deprivation of liberty had taken place (or will take place) and if this was in the person's best interests, particularly as the possibility of cumulative restrictions being applied did not seem to have been considered in such cases. It was noteworthy that in each of these eight cases, the families' support for the use of restraint or detention was quite influential in the decision-making process. However, whilst the interests of clients have to be balanced against the interests of their carers, allowing a family's views to take precedence can result in the clients' best interests becoming marginalized and their needs not being adequately met. The clients' perceived aggressive or 'challenging behaviour' also influenced the use of restraint (in the cases where DOLS applications had not been made). Differences in professional status and power also exerted an influence on best interests processes, particularly where doctors had more decision-making authority. A lack of resources to provide 24-hour homecare was additionally shown to contribute to decision-making about detention. In each of the three cases where the clients had been detained in care homes, but DOLS assessments had not been undertaken, the use of strategies of deception to achieve admission, when perhaps the Deprivation of Liberty Safeguards should have been applied instead, meant that the clients' legal right to liberty may not have been adequately protected.

4.4.6 Informal conversation

Although the majority of the online cases were carried out by virtue of at least one meeting (see Table 15 above), nevertheless meetings were not the only way in which best interests decisions were made. Participants themselves generally valued the structure and cohesion which were brought by meetings, although there were also comments at times about distress caused to those who lacked capacity, when they were included in these more formal processes. A question could be posed about the overreliance of participants on meetings,

and whether these were in fact objectively successful in achieving a better outcome for participants. By coding data from the telephone interviews for 'outcome' measures of success, the following factors seemed to indicate the value of meetings:

- Meetings were useful in order to support care staff, family or other hands-on workers, since they were helped to see their actions and decisions in the wider context of best interests.
- Meetings were often part of a wider structure which enabled the best interests process to achieve a gravitas and formality which positively influenced the outcome. This was especially so in cases where there was some conflict, for instance with the person lacking capacity or with family members.
- Information sharing could also occur within meetings, which could positively influence complex cases where people had to make up their minds, for instance between two options in difficult medical cases.

There were a few cases in which meetings were not associated with better outcomes, since they could cause delays. At their worst, meetings enabled the decision maker to avoid playing their role, by seeking to ensure that everyone was in agreement. While consensus seeking was a key theme in this research, it could be a problem when it caused delays or when there simply was not a consensus to be reached. There were some strong views from participants in medical or care settings that medical practitioners do need to be responsible for medical decisions, for instance in end-of-life situations. However, formal meetings were seen to be valuable in those cases, since they could hold medical consultants or general practitioners to account.

Informal processes were discussed particularly at the interview stage (see Report 3, Section 4.1). In some cases, the best interests process was an informal affair, and for instance could be carried out at the patient's bedside. The nursing home manager in one case explained clearly how safety and urgency can both impinge on the process of decision making:

I mean there are times obviously you've got to maintain safety, you've got to make a decision quite quickly and there might not be time to consult people earlier. In other decisions you've got time to speak to the family, the individual, the people that know him.
(F22a)

Only a small number of everyday decisions were identified in this research, which could indicate that the MCA is not sufficiently salient in everyday practice, for instance in care homes. However, we took pains to follow up some of these matters in the interviews, and found that everyday or less 'serious' matters were often more appropriately resolved through informal conversations. Sometimes a particularly sensitive issue, such as personal hygiene, would not be appropriate to discuss in a formal way around a meeting table. In addition, the prior knowledge of the client and the degree of consensus surrounding this were identified as further factors in promoting informality in a best interests process. If everyone agreed with a decision in advance, then there would have been no point in having a formal meeting. That was so in one of the interview cases (F23) which we give below as an example:

A man in his late 40s had been informally admitted to an acute psychiatric male ward, with a history of schizophrenia and alcohol abuse. He was severely self-neglecting, had been hearing voices, sleeping rough and had not been taking his medication. When he was admitted to the ward, he was wearing multiple layers of clothing and had not changed or washed for about a year. Staff were concerned about his ability to look after himself and also about his physical well-being, particularly as it was difficult to carry out a physical examination without removing his clothes. The best interests decision was made about removing his clothes and giving him a bath, by the different staff involved gathering around his bedside, and informally discussing the situation with the man himself. (F23, Report 3)

It should be noted that in informal processes, it was perhaps even more important to take care in recording the process, the discussions held and the outcome, so that the best interests process was transparent for everyone. However, it should also be recalled that this research study focused primarily on best interests decisions made about major, serious matters. In the everyday run of life in a care home, for instance, staff will necessarily be making best interests decisions on a day-to-day basis. Some of these were discussed with staff at interviews and on the telephone, and they pointed out particularly the value of detailed personal knowledge about the preferences and needs of individual clients. In many cases, these could be recorded in advance in care plans or in person-centred plans, and many of these examples came from settings involving people with learning disabilities:

People don't move on a lot, some of them are just decisions that are recorded in care plans, so we can say, you know, there are things that you have to do, be it, these are the indicators for using a physical intervention with somebody, or these are the indicators for giving

somebody additional medication, if they're upset. To things like, Mr Jones can't make decisions necessary that are appropriate clothing for the weather, so if it's really cold outside can you make sure he's got an extra jumper, and things like that. A lot of them are recorded in the care plans already. But equally there are things that we'll say, you know, we had to stop a person doing this today because we didn't feel it was in his best interests. (F08, Report 3)

4.5 How are best interests decisions reached?

The online survey revealed that participants regularly reported that people's past and present wishes had been considered (90% of all cases), as well as their beliefs and values (76% of all cases). Further, of the 270 respondents who answered the question about how the final decision was reached, 80% (215) said that all the information from the process of deciding the person's best interests was used to make a decision.

Table 18 How the final decision was made in the online survey cases

	Number	Percent
All the information from the process of deciding the person's best interests was used to make a decision	215	56
The decision was based mainly on previous knowledge or other information about the person rather than the information from the person's best interests process	22	6
The information was given to someone else and they were asked to decide	13	3
Don't know	10	3
Other	10	3
Missing	115	30
Total	385	100*

*The total does not equal 100% due to rounding

Having overviewed the structural processes and patterns in best interests decision making it remains to take a closer look 'inside the meeting'. We had hoped in this study to have opportunities to observe a small sample of meetings and other processes in a final stage of the research, but time constraints and difficulties in obtaining participation meant that the observational stage was not carried out. Nevertheless, some points made in discussion with our research participants gave us the next best opportunity to gain an 'insider's' view on what a best interests process looked like, and how a best interests decision was actually reached.

In the telephone survey, we noted in Report 2 how important it was to ‘get people round the table’ (Report 2, Section 3.3.2). This was in order to listen, to share information and to reach a joint decision. Interviewees spoke about the value of a meeting to clarify matters, but that was only successful if clarity was first achieved about the roles of individuals and the purpose of any particular meeting. The business of achieving that clarity was explored further in interviews. In Report 3, Section 4.4, we discussed the points about a chairperson’s role in regard to clarity. As was seen in F09 (Derek’s story in Appendix A), the chair’s role included:

- Stating the parameters of the meeting
- Knowing and sharing the legal status – what the meeting can and cannot do.

In many cases, there were multiple issues in the best interests decision to be made, and a particular client or patient may have presented with a long history of problems. Therefore it was important for a best interests meeting to actually define and focus on what the decision was, rather than to be side-tracked into discussing the client in general. For instance, the MCA advisor in one of the interviews about a care home case (F13b) emphasised to staff that the decision they had to make was about hygiene, rather than any other aspect of care.

Having said that, the process of reaching a best interests decision usually involved many informal meetings, preparation and discussions with the client and with others who were close to him or her. Those discussions were also seen to form part of the overall best interests process, and were best carried out:

- In ways that were sensitive to the ‘best time of day’ for a particular client
- By involving familiar staff, friends or family
- By using accessible information strategies, including pictorial means, photos or videos to engage people and help them remember.

If a person lacking capacity was to be invited to a meeting, it was even more important to ‘get it right’. As we will explore below, there were occasions when attendance at a meeting backfired. Ways to include people lacking capacity will be further explored in Section 5 of this report.

One of the interesting features of best interests decision making explored in Report 3 was the tendency to break the decision down into different levels. Quite often, the central best interests decision had already been made by the time of any meeting, particularly if the client was to be involved. However, one decision led to a whole raft of sub-decisions, which were

effectively about the implementation of the major decision. Typically, here, the decision might be about someone having to move into a more protected environment, as Derek did in F09 (Appendix A). Having made that overall decision, there were then many ways in which Derek could and did get involved in the decision making about where he would move to, with whom he would live, how he wanted his decorations to look and so on. Identifying these sub-decisions was often a vital way of engaging people in choices about their own life and also in finding creative alternatives. Instead of simply agreeing that an older person should be moved 'to a care home', for instance, the point then became to match her or his needs and preferences to the qualities of particular homes. It was often the small details which really mattered, and could make the difference between a good and bad outcome for the client, as we will explore in Section 9 below. What is important here is to note that *someone* needs to ensure that all alternatives are actually 'on the table' and that the decision(s) to be made are then clearly delineated.

5. Including the person lacking capacity and significant others

5.1 Keeping the person at the heart of the process: meetings

The online survey results showed that best interests processes were most likely to involve the person lacking capacity, either in a series of meetings (36%: 140 cases) or in a single meeting (21%: 80 cases). Table 15 indicated that only 12% of cases (46) definitely did not involve the person lacking capacity in any meetings, while a further 9.5% (37) respondents were unsure or marked as 'other'. However, there was a significant difference between people with learning disabilities and those without learning disabilities, when considering the best interests process. People with learning disabilities were significantly more likely to have decisions made for them at one or more meetings that did not involve them (see Tables 39 and 40 in Report 1). Further, they were also significantly more likely than other groups to have had other people consulted in the decision-making process to decide on their best interests. For those with dementia, the opposite picture emerged, with people with dementia significantly more likely to be included in meetings, as compared with other groups.

Being involved in a meeting is of course not the only way to have one's views and preferences taken into account. Of those cases where the person lacking capacity was *not* invited to a meeting 27 (59%) were thought to have been as fully involved as possible in the decision-making process, and over three-quarters 37 (80%) were said to have had their past and present wishes and feelings taken into account. Most respondents who said that the person lacking capacity was not at a meeting (41; 89%) thought that overall, the person's best interests had been decided upon quite well or extremely well. A small number (5; 11%) felt that the decision-making process for these people had been quite poor.

In the telephone survey, the problems of including people in formal meetings were spelt out. Section 3.4.3 in Report 2 explores cases in which meetings had been unnecessarily distressing for the client, when they disagreed with the decision being made. A young woman with learning disabilities went to a meeting where she 'disengaged from the process' because she did not like to be challenged about her views, and another person was mentioned who was invited to a meeting but declined. A further nine cases had involved the person in a meeting, but it was said variously that the person 'didn't have a clue about what was going on' or just wanted to go home. In one case, a relative of someone with brain injury

said: “he would listen and then at the end he would say, *Well I don't understand what you've been talking about...*He was just...he hasn't got the...I think it's the concentration, if you like.” (T04)

These problems were re-iterated at the interview stage, but some more insight was gained into ways in which meetings could work better for the person lacking capacity. For instance, Derek in Appendix A of Report 3 (F09) was invited to the second part of a two-part meeting, following some lengthy preparation of all concerned. At the first part of the meeting, some difficult issues which involved police presence and safeguarding decisions were discussed. In the second part, by all accounts, Derek was involved successfully in discussions building on his own wishes to have a say in his own future lifestyle. As was mentioned by the psychologist in the case, the second part of the meeting started by explaining to Derek the purpose of the meeting, and exploring with him what he understood by words like ‘risk’ and ‘danger’ and how he would keep himself safe. Effectively, as the care manager explained, Derek did not attend any meetings until decisions had already been reached.

5.2 Facilitating communication

Facilitating communication in a person lacking capacity was often more effectively accomplished outside a meeting, according to the participants in interviews. Section 5.1 in Report 3 explores how participants sometimes were able to delay the decision, so that people could become more familiar with each other, and would be better able to communicate. The second point made was about the value of informal, relaxed communication which did not at first specifically focus on the problem area. In other cases, non-verbal cues were used to try to work out what a person wanted. That happened not only with people with learning disabilities, but also with those with dementia. As we have emphasised with all these examples, the key to most strategies was about building up a rapport with the person.

Information strategies were also important, for all client groups, including those with mental health problems. In order to understand a person’s wishes and views, it was important to try and explain as much as possible to the person about the decision to be made. For instance, the woman who had a uterine prolapse was given pictures of the body, to try and understand what was happening in her own body. Pregnancy was also the subject of pictorial explanations, as were sexual encounters generally. Communication is a two-way affair, and

will take place over a period of time, with real experiences and encounters feeding into a person's understanding of what is going on. An illustration is given below of effective communication strategies in action.

A man with autism and some complex communication and learning disabilities had been living in an NHS residential facility that was due to close as a result of local policy. He had been assessed as not needing continuing health care, and so was due to move into a flat on a 'supported living' basis. However, the interviewee felt that time needed to be taken to consider the man's needs carefully, before he moved. He therefore raised this matter with the social worker, and fought hard to get things in place so that the man would have a well-managed move into a situation where his needs could best be met. An accessible information picture book was made with the man, who was taken to see the new house which was proposed. Photos were taken, and the interviewee had continued conversations with the man about the place.

One of the issues was about how much support the man would need, at least at the outset, in his new home. A person-centred plan was worked out for the man, and shared with staff in his new home. There was also a good deal of individual preparation with the man himself. They took down his pictures from the wall, for instance, and they went over to his new place to hang his pictures. At the time of the interview, he had moved successfully into his new home. (F08, Report 3)

5.3 Taking account of present wishes and past values

What then was the outcome of involving people in best interests processes? The vast majority of respondents in the online survey said that the person's past and present wishes and feelings had been taken into account (90%) and/or that the person's beliefs and values (e.g. religious, cultural or moral) had been taken into account (76%).

However, it was unclear from later stages of the research whether 'taking into account' really meant that the decision itself was changed. Sometimes, involvement was simply to ensure that the person knew about the best interests decision, and as discussed in F09 in Appendix A, involvement was also an effective way of persuading a person, or bringing them on board with a particular outcome. Did the involvement in fact ever influence the decision? A clear example was given in one of the telephone interviews (T13) where an older man with

dementia was being discharged from hospital. A small informal meeting was held between him, the OT in the hospital and his niece. At that meeting, contrary to the expectation of the OT, the man said that he did not want to move into a care home near his existing home area. Instead, he wanted to be near enough for his niece to be able to visit. That intervention did change the decision, although when followed up later, it was found that the man had after all moved into a local home, due to a lack of places being available where he had wanted. Nevertheless, the niece was still able to visit regularly.

In other cases, careful observation and longer-term communication with a person influenced a decision, for instance against carrying out an operation or procedure, which would have interfered with their lifestyle and preferences. A clear example of that type of 'listening' was Case F01, where the young man with profound learning disabilities did not have a PEG tube inserted, so that he could carry on enjoying the one thing he liked in life, which was his food. Small details about a person's preferences were sometimes noticed by family and friends, but also by care staff who were close to the person. The son of an older woman with dementia took his mother's sewing machine into the care home, so that she could continue to enjoy her lifelong hobby. In Lily's story (Case 12 in Appendix A of Report 3), the nurse who knew her best had arranged for her favourite films to be available on DVD in her new home.

People's past values were also mentioned, although only occasionally, in interviews. In the telephone survey, one community psychiatric nurse described an older woman with mental health problems who had developed dementia. She had known her quite well over a period of years, and became concerned that the woman could not manage her money by herself, being unable to get to the bank because of her physical condition. As the interviewee said, the woman had *"always lived quite a simple life, but has always liked nice things at the same time. But because nobody could access her money, including her, things had sort of deteriorated over time, and there's been no way of replacing them."* (T09 in Report 2)

5.4 Involvement of other significant people in the BI process

As will be recalled, the overall process used to decide on a person's best interests was most often a 'series of meetings involving the person, the decision maker and others who knew the person'. Table 16 above shows that 140 (36%) of respondents in the online survey had used that process, and a further 80 (21%) had been involved in a single meeting, also

involving the person and others who knew the person. Over half the sample, therefore, had had meetings with people who knew the person lacking capacity, and the numbers may have been greater, as meetings which did *not* involve the person themselves (46; 12%) could still involve others close to them.

As we have argued above, meetings are not the only way to consult, listen and involve people who lack capacity. Neither are they the only way of involving other significant people. Table 19 below shows that 264 (69%) of respondents in the online survey in fact felt that people close to the person were in fact consulted about the person's best interests.

Taking this group together with those who said it was not possible or appropriate to consult everyone, the vast majority (336; 88%) of respondents felt that people had been consulted, and most of those (290; 86%) felt that their views had been taken into account. As Tables 48 and 49 in Report 1 show, people with learning disabilities were significantly more likely than others to have had other people consulted about their interests.

Table 19: Consulting other people (online survey)

	Number	Percent
People close to the person were consulted as to what would be in his or her best interests	264	69
People close to the person were consulted but it was not appropriate to consult everyone	44	11
People close to the person were consulted but it was not possible to consult everyone	28	7
There was no-one with whom it was appropriate to consult	22	6
It was not possible to consult anyone	16	4
People who should have been were not consulted	7	2
Not sure	4	1
Total	385	100

Given this encouraging picture of consultation and involvement, we were interested to see in the telephone survey and in the interviews how that consultation was conducted, and whether it actually made a difference to best interests decisions. First, it was important to know *who* to consult, and to ensure that the full range of possible consultees had been

approached. In this regard, several telephone participants mentioned the care they had taken to assess appropriate consultees, who may be different from those involved in the capacity assessment:

It was seen as almost a different process. And we didn't necessarily want the same people who assessed his capacity making the decision around what was in his best interest, because they didn't necessarily have the right skills to do so (T15)

In health care or long-stay settings, respondents were clear about the value of consulting with those who were closest to the patient, who were largely the nursing or care staff. However, there were also efforts made by social care respondents in particular to seek out those who may have known the patient or client in the past. This often included relatives who had been previously unknown within the setting, such as a grandson, nephew or other more distant relative. In one case, this resulted in actually finding that this relative had a LPA in place, which had not been previously realized.

In the face-to-face interviews, participants also spoke about those who, in their opinion, were not appropriate to consult. Much of this talk hinged on mistrust or suspicion of the motives of certain people, particularly where there were concerns about financial matters, and in eight cases this related to family members who had been seen to profit from the confusion or impairment of their disabled relative. In one case (F 21a), in a decision about relocation, there was also suspicion of a landlord who had a financial interest in retaining his tenant.

In at least 24 of the telephone interviews, the interviewee had already known the person lacking capacity well, over a period of time (see Section 3.4.1 of Report 2). In a further five cases, interviewees were discussing cases relating to their own family members or friends, and so we had plenty of evidence about the importance of familiarity and trust between people. The first point of contact between someone leading a best interests process and family/friends was often when there were attempts to communicate and find out more from the person lacking capacity. In urgent situations, it was often vital to contact a family member, in order to find out how the person normally communicated, and to enable him/her to be supported to express their views. Therefore, a close and trusted person has a function at that point of simply supporting the person lacking capacity. In at least 20 cases, a close or trusted person (such as family or friends) was brought in to support the client. That person could be a warden from a housing association, a care home manager, or a family member.

However, in very urgent cases, that contact could delay matters unnecessarily. For instance, in T24, an AMHP (approved mental health practitioner) realised that a woman he was visiting had locked herself in, and was losing consciousness. He contacted the ambulance service, and together they agreed that the woman did lack capacity at that point, and had to be taken to hospital. It transpired that she had taken an overdose, and when her son was then contacted and came to see his mother, he was very relieved that swift action had been taken.

In cases that were more considered, and had a longer timescale, family members played even more important roles. In the telephone survey, for instance, we were told of many cases in which the views of a family member were absolutely key to the best interests decision and the outcome. In T35 for instance, a man with mental health problems had been admitted to a care home where his movements were severely restricted. A DOLS application had been made. He had dementia as well as longer-term psychiatric problems, and had started to refuse food. The mental health professional who spoke to us described the family's viewpoint, which was basically that the man's decline was entirely due to his dementia. They were in favour of not intervening, and according to our interviewee, the psychiatrists allowed the family view to dominate the decision:

I think they held store by this very much, that they felt that if the family were saying this, therefore the family should be the ones making the decision that he should be left to...should be made as comfortable as possible while he was allowed to die.(T35, Report 2)

Not all cases were so extreme. Yet family views were also one of the dominant factors in T28, which was the case in which a man with learning disabilities was being considered for dialysis, and in at least another dozen cases in the telephone survey. That was so both for health and for social care decisions. For instance, in T45 a woman with learning disabilities had lived in a private care home which was predominantly for older people. Her brother did not want her to associate with other people with learning disabilities, but problems arose when she started to develop dementia. It was then considered that she would have to move to more suitable accommodation where her needs could be met. At that point, however, the care home manager said that the brother decided entirely where the best place would be. It seemed that there were many cases in which the family members had a very strong voice, not just in speaking up for what their relative would have wanted, but in effectively making

the decision. As one specialist nurse said in Report 3 (Section 5.3):

I don't think I would like to make decisions regarding patients' treatment purely on what I felt was appropriate or not appropriate, really. I think it has to be that everyone that's involved with that particular individual, that all their opinions are taken into consideration really, definitely. (F11)

Finally, another important way in which family members or friends were involved in best interests decisions was to tell people about the small details in people's lives, which mattered to them. The solicitor who told us about her father who had a brain injury was adamant about what mattered to him; his book and stamp collections were part of 'who he was', and so it was really vital that they were kept intact, and that he could still see them from time to time.

5.5 Disagreements

Although the majority of respondents in the online survey reported that there had been no disagreement, nevertheless 65 reported some type of conflict. Table 20 shows how these cases were distributed over the different decision-making contexts.

Table 20: Whether or not there had been any disagreement about the person's best interests according to the type of decision made

	Healthcare (%)	Personal welfare or social (%)	Property financial affairs (%)	More than one matter (%)
Yes: There were disagreements about the person's best interests	15	21	11.5	24
No: There were no disagreements about the person's best interests	85	79	88.5	76
Total %	100	100	100	100
Total number	182	86	26	72

The 65 respondents who thought there had been disagreement about the person's best interests were examined in more depth. The majority (35; 57%) reported that the decision had been made over a series of meetings, which was a greater proportion than the 48% overall. Disagreements were more frequently reported by those who had been consulted in best interests processes, but were not the decision maker (21%, compared with 13%

overall). The interviews further revealed how family members were sometimes seen not as 'allies' but as problems (Section 5.3 of Report 3). However, as noted in the telephone survey, conflicts could be between professionals, as well as between family members and professionals. Additionally, there was also a large number of cases reported at the interviews stage where the conflict was in fact between the views of the person lacking capacity, and those who were supporting and advising him or her.

In those conflicts with families, consensus decisions were always preferred, and so professionals appeared to make great efforts to ensure that family members were 'on board' with a decision. However, there were cases in which the attitude or practices of a family member or friend lay at the root of the problem, and a best interests decision was being taken that excluded or regulated that behaviour. For instance, as discussed in Report 3, in F12 (Lily's story in Appendix A), there had been allegations of financial and personal abuse by her grandchildren, and so the best interests process was at least partly about protecting Lily and ensuring that she found a place to live away from her grandchildren; in this case, as in at least two others, there were also suspicions of financial abuse. In F16, for instance, a woman's daughter was suspected of having profited unduly from her mother's share of the finances. As they shared the mortgage on a house, the appointees for her mother decided that it would be in the older woman's best interests to sell the house back to the Building Society, and release the cash for the woman's use. In these cases, instead of involving and listening to family members, decision makers were essentially finding ways to exclude them from the lives of the person lacking capacity.

Between those two extremes, of course, there were several cases in which a relative or friend was not entirely considered a partner in the best interests process. A case was described in the telephone survey, for instance, which related to the best way to support the mobility of a young man with physical and learning disabilities. The complex role played by a parent in this case was interesting, and not untypical of other cases. It is given here as an illustration.

A man with learning difficulties and challenging behaviour, living in a care home, was attending a day centre, but also spending time at home with his mother. Our interviewee, who was a community learning disability nurse, explained that it had been brought to light that his behaviour needs were being met in different ways in these three settings. His mum responded to his outbursts by giving him what he wanted. However, in the care home, staff

couldn't understand his outbursts and ignored them in an attempt to distract him. In the day centre, he had a very sensitive speech and language therapist (SLT) who helped him to communicate via a communication board. The mother had made a complaint about him not having opportunities to communicate in his care home. In fact, when it came to the best interests meeting about this man, the SLT commented that the man seemed quite happy at home when his mother was with him. The BI process took place at a multi-disciplinary care meeting, to which the mother was invited, and the decision was documented that this man should only be responded to if he did not shout. However, implementing that decision very much depended in the man's mother cooperating with it. The interviewee spoke about a subsequent meeting to 'get the carer on board'. Ultimately, this best interests process focused on the man's physical needs, but in order to implement those successfully, lifelong practices of care within his family had to be altered. (T38)

In the case given above, then, it can be appreciated that a family member may well feel that they know best. However, their own decision will not always influence professionals involved in the case, and ultimately the decision is not theirs to make. Nevertheless, it was essential for the family member to play their part in achieving the outcome of the decision, and so the whole process became very much one of education and persuasion. Just as professionals often had to *persuade* the person lacking capacity to comply with a decision, so also they also had to work at persuading relatives and friends. For instance, much care was taken in F12 (Lily's story in Appendix A of Report 3) to persuade her grandchildren. They had hoped that their grandmother would transfer ownership of her shares to them, and they had to be kept informed both of the decisions that had been made about the care home, but also about the fact that their grandmother would not be able to change her financial arrangements. All those things were clearly not just about supplying information in a bald sense, but also encouraging the family to accept and agree.

Some family members were distant relatives, who may have been out of contact with the person lacking capacity for a while. When they did then express a view, that had to be tempered by the knowledge that they may have been 'out of touch' with the person's ongoing needs and views, as was argued by the OT in F06, in relation to the grandson of a woman with dementia who was being discharged from hospital. Although the grandson spoke up for his aunt's wish to go home, he was felt not to know how she had now developed a fear of living on her own. Therefore, relatives' views sometimes had to be calibrated against their

actual closeness to the person for whom the decision was made, and professionals had to be aware of how to position that relative in the matrix of decision-makers and concerned parties. Where there was mistrust, as seen above, they would be excluded from the decision, but in most other cases there were diplomatic attempts to “recruit them to the cause”.

Turning to conflicts between professionals, those disputes were associated with a sense of disempowerment by those who felt unable to speak up for the client or patient they knew. That was so, for instance, with the appointees in F15, where they felt they knew the client better than the social worker who overturned their decision to protect a young woman from a potentially harmful purchase, where her money would be likely to run out. There was also a strong sense of disempowerment amongst the care home staff dealing with GP decisions in end-of-life cases, in T42. A very unhelpful feature of some of these cases was the feeling that there were ‘factions’ involved, where for instance, legal professionals and social services clashed in their views of the case.

Conflict resolution was therefore a key skill in managing a best interests process. As we have seen, a particularly sensitive type of conflict was one in which relatives of a person lacking capacity were suspected of abuse. Those under suspicion were generally excluded from meetings or discussions about the decision, but were subsequently informed about it. In some cases, as explored below in Section 6.2, an IMCA was sometimes brought in by the person leading the best interests process, in order to mediate or influence the family. An even more sensitive conflict, though, was when a relative’s own needs had to be weighed in the balance. A family carer sometimes had health problems or other needs, which meant that his or her best interests also had to be taken into account, since they would impinge on the best interests of the client. Much of this was about subtle persuasion, as well as chairing skills, since there came a point when the decision had been reached for a person to be better protected, to move to a care home, or to have their self-care enforced. The task then was about enlisting support for that decision, so that it would have the best chance of being successful. The art of persuasion is explored in some detail in Appendix A of Report 3, particularly in relation to Derek’s story (F09).

As pointed out in Report 3, many of these conflicts were inevitable, since they were a natural result of situations in which a single solution was not obvious. If it had been, then there would not have been a best interests ‘process’ at all. Therefore, a certain amount of conflict was, in

most cases, to be seen as 'in the best interests' of the person lacking capacity. It follows that the best way to resolve those conflicts was always to keep at heart the person themselves and their wishes and preferences. The best way of resolving any incipient conflict was a sensitive consideration of what was most important to the individual, and a strong desire to defend that person's rights.

It was only rarely that we spoke directly with family members themselves in the BIDS project, as that was outside the scope of the original research brief. Despite the intentions of the team to include carers in the interview stage in particular, there was a reluctance by decision makers to pass on research information to people who had been involved, and this is discussed in 1.8 of this report. However, from the small amount of information we had, we felt that carers' views definitely warrant further investigation. Five of the telephone interviews were about the point of view of a carer, and in all five cases, the family member had been effectively disempowered. The only reason some of these cases were successful were that they had been reported by people who had professional expertise to bring to their role as a family carer. The themes that started to emerge were bewilderment, stress and indeed anger. Occasionally, a friend or family member had managed to arrange matters so that the best interests decision did in fact take into account their own views. However, some of these were professionals who had become involved in a best interests process relating to their own relative or friend; these included a solicitor, a staff nurse and a clinical practice educator. The remaining two were retired men who had had professional careers. Their main concern was always for the detail and precise arrangements to be right for their relative or friend. For instance, the staff nurse in T08 described a case she knew through her church community, in which a man with learning disabilities had to move out of his mother's home. She and a friend of hers looked at options for this man, which would be near the church he attended and the people he knew. However, the hospital had already sent him to a different care home with his sister, whom he did not like. These few interviews with friends or family were timely reminders that there is always more than one perspective on any decision.

6. The role of the IMCA

Perhaps in part because this research initially targeted people who had made a best interests decision with recruitment promoted in local authorities and NHS Trusts, only a relatively small sample of IMCAs participated in this study. Seven respondents to the online survey identified themselves as IMCAs, just one took part in the telephone interview stage, although several cases that were discussed with others had IMCA involvement. At the face to face interview stage, mindful that we had not yet gained a perspective from IMCAs, we undertook a targeted approach and successfully discussed four best interests cases with IMCAs directly.

In addition, we gained insight into the perceptions and experiences of other people who had instructed, or been consulted by IMCAs throughout. For example, in the online survey, whilst just 7 IMCAs completed the survey themselves, they were involved in 22 of the 93 (24%) personal welfare or social care cases, and in 47 of the 184 (26%) health care decisions (Table 55 in Report 1). In keeping with our analysis elsewhere, the majority (59%) of the personal welfare decisions related to a change in accommodation, and for health care decisions, 60% related to consent to a serious physical health care treatment.

6.1 IMCAs are involved in making the decision

An interesting observation from the small number of IMCAs who completed the online survey was that 4 of the 7 stated that they were either a joint decision maker or part of a multi-disciplinary team who made the decision. Of course, the IMCA role should not involve making a best interests decision; however this survey finding suggests that some IMCAs do see that as part of their role. This may, in part, be explained by the preference for best interest decision making processes which involved a meeting, or series of meetings (discussed in Section 4 of this report). As the IMCA is involved to represent the person lacking capacity we might reasonably expect them to attend meetings where decisions for that person are discussed. Projecting forward from this presence, there is a question of interpretation here: IMCAs may believe that they are 'decision makers', or at least that they have some agency in the decision making process. We would have been more concerned if IMCAs had told us that they were not involved in the decision making process.

6.2 IMCA being brought in to mediate

Although an IMCA should only be instructed when there are no family or friends available who are 'appropriate to consult', we came across 5 instances where IMCAs had been involved despite the presence of family. As we discussed in Report 2, 3.3.5, these cases all included a dispute between professionals and the person and/or their relatives. This is similar to findings by Redley *et al.* (2008), who found that 20% of family and/or friends were deemed inappropriate to consult, due to a conflict of interest. In the extended case of 'Lily' (F12 in Report 3), it might be questioned whether it was appropriate to consult an IMCA, as there were family members available to represent her. The professional team felt the need to instruct an IMCA here because of concerns about possible financial abuse by her grandchildren. The IMCA offered the decision making team an objective assessment of Lily's wishes which they did not feel Lily's family could be trusted to do. A similar motive applied to T14. In this case there were concerns that an older woman was being restricted of her freedom by her cousin, hence an IMCA was instructed to add weight to the professional team. Using the IMCA to persuade family members was a feature of both T22 and T28.

The view among professionals here then appears to be that an IMCA can be useful where there are voices dissenting with those of the decision makers. This approach, albeit contradictory to the requirements of the MCA was also found by Redley *et al.* in 2008; our research revealed how useful the intervention of an IMCA can be in conflict situations. Perhaps a summary of professionals' attitudes to the role of an IMCA should be left to the consultant interviewed in F12c: *Well, they're useful when we get stuck!*

6.3 Disputed IMCA practices

Not all of our participants were complimentary about their experiences of working with IMCAs. This finding in some ways contradicted Townsley & Laing's (2011) findings about the positive effect of IMCA involvement, but it must be remembered that the two studies were based on different points of view, with Townsley *et al.*'s data coming directly from IMCAs themselves. In the current research, different points of view helped us to see where precisely IMCA involvement might be most useful, and where it was problematic. For instance, in T12, the solicitor was quite critical of the approach of the IMCA in a case where a change of accommodation for a man with dementia and physical support needs was being considered following a period in hospital. He was about to be discharged from hospital, and concerns related to whether he would be able to cope physically in the family home; hence it

was being proposed that he should be moved to a care home. The IMCA had been instructed to represent the man, but the interviewee felt that the IMCA had not (but should have) taken into account the man's wider best interests. In particular she felt that the IMCA did not consider the demands on the man's wife to support him physically in the family home. This is a dilemma in the IMCA role. Under the MCA, the *decision maker* is responsible for weighing up what would be in the person's best interests, so it could be argued that the IMCA had, in this case, rightly advocated for what the man told her he wanted (ie that he should like to move back to his own home).

6.4 IMCAs challenging decisions / assessments

An important requirement of the IMCA role is to raise any issues of concern with a decision maker. We saw in the online survey, that there were disagreements in 19% (9 of the 47) healthcare cases where there was IMCA involvement, and in 31% (7 of the 22) personal welfare / social care cases. Whilst the limitations of the online survey do not tell us whether these disagreements emerged because of the involvement of the IMCA, there were more disagreements reported in cases involving IMCAs than in the whole sample. When looking at all cases, there were disagreements in 15% (27 out of 184) of health care decisions, and in 21% (18/86) of personal welfare/ social care decisions (Table 19). This could indicate of course that IMCAs were included in cases where there were already disputes. However, perhaps an explanation for some of the negative attitudes towards IMCAs discussed in Report 2 could, in part, be because they challenged and disagreed with professionals. When we spoke to IMCAs for Report 3, they gave us examples of having questioned assessments of capacity, and having ensured adherence to the five principles of the MCA.

6.5 Awareness of the IMCA role

A theme running through this section appears to be a lack of awareness of the finer details of the IMCA role. Manthorpe and Martineau (2010) also indicated that there is a need for social workers to be better informed about their legal responsibilities to refer to an IMCA and to be more assertive about ensuring that referrals are made. This lack of awareness was demonstrated in the examples of ineligible instructions, where family members were available to consult. In Report 2, 4.2.4 we gave examples of staff in clinical settings admitting to their lack of knowledge of the role of the IMCA, or how to go about accessing IMCA provision. This continued in the more in-depth face to face interviews, with an IMCA herself referring to an occasion where she had been asked by a consultant to sign a consent

form for a person she was representing to have an operation (Report 3, 5.4). Quite how this lack of awareness can be overcome is not a question we can answer in this research. However, there was a sense that in some cases, awareness of the IMCA service was increasing, even in previously difficult to access areas such as the intensive care unit where this clinical practice educator worked:

We've never had an IMCA in, but recently we've had some cases where it becomes more appropriate to think that way. We're getting into the mind set of thinking that way. It used to be just sort of the family that we counted on. And more and more frequently we're finding there isn't family, or family doesn't want to be responsible, and it's probably not appropriate for them to be responsible. [T7]

6.6 What do people value about the IMCA role?

The positive comments we received about IMCAs from professionals suggests that the aspects of the role that are valued include the time and opportunity they have to 'get to know' the person lacking capacity, through discussions with different people who are involved in that person's life. In doing so they are able to bring information to the decision making 'platform' that particularly medical professionals would not be able to access. This finding was also echoed by Townsley *et al.* (2011). Delivering this information, in timely reports, is also valued, as the nutrition nurse outlined in Report 2, 3.3.2:

She was very good. She sort of contacted me to get details of my assessment and what I'd found before she went and did her assessment. She then communicated her assessment, she did a written report and sent that to the consultant at the hospital who's part of the multi-disciplinary team and who would be the consultant that would be placing the PEG. [T29]

Apparently there is common ground between what professionals want from IMCAs and what IMCAs told us that they needed in order to be effective. The concerns expressed about IMCAs often focussed on issues of timing. We were told of two cases where a person lacking capacity had died before the IMCA had been available to meet the person. For their part, IMCAs felt that they benefited from being instructed as soon as possible; the quicker they were able to become involved, the more able they felt to advocate for their client.

7. Record keeping

At each stage of the research we asked participants how they recorded details of the best interests decision. At the later, qualitative stages of the study we also asked people to describe how assessments of capacity were recorded, as well as expanding the discussion about what records were kept about best interests to include both the process *and* outcome. We were also interested to find out about what supplementary forms of record keeping were associated with best interests decisions.

7.1 Use of standard forms / pro-formas

Predictably, given the magnitude of the decisions discussed in this study, there was an overwhelming preference for *formal* recording of best interest decisions. Thus, in the online survey we reported that over two-thirds of all respondents had kept a formal record of the best interests decision. Table 21 shows that a detailed note about the best interests process was made by 36% of all respondents (n=137), and a standardised form or pro-forma was used by a further 34% of respondents (n=130). Only 1% of respondents (n=4) stated that the best interests decision was not recorded. When we undertook further analysis of these responses, looking specifically at cases where a decision was recorded, we found that the most likely mode of recording health care decisions was with a detailed note of the process and outcome. The other two main decision types (personal welfare / social care decisions and property/financial affairs decisions) were most frequently recorded using a standard form or pro-forma (Report 1, Table 66). When we looked at the mode of recording further, we noted a statistically significant finding, that where the person lacking capacity was someone with dementia, the best interests decision was more likely to be recorded using a standardised form or pro-forma.

This preference for formal recording was reinforced in the more discursive telephone interviews. As we discussed in Report 2, Section 3.2.1 many of the professionals we spoke to used a pro-forma to record assessments of capacity. The largest proportion of professionals who recorded the assessment of capacity using a pro-forma were those that we categorised as social care practitioners. Similarly, when looking at the mode of recording best interests processes and outcomes, the vast majority of social care practitioners used a pro forma. During the course of the research we were able to collate copies of several of these pro-formas. In several cases, these forms of documentation were common across

disciplines – for example in Area 2, the standard capacity assessment form and best interests checklist had been adopted by the local authority, the NHS Trusts and, as we found in case T40/F13, they were also used, with some familiarity, in private care homes.

Table 21: How the final decision was recorded in the online survey responses

	Number	Percent
A detailed note was made about the process and the outcome	137	35.5
A standardised form or pro-forma was completed	130	34
A brief written note of the decision and outcome was made at a later time (e.g. in a hand-over book, daily record sheet, the person's file or records)	55	14.5
It was recorded by someone else (for instance in the minutes of a best interests meeting)	29	7.5
The decision-maker told someone else what had been done	6	1.5
It wasn't recorded	4	1
Don't know	24	6
Total	385	100

Whilst this numerical data tells us something about the preference people have for documenting best interests processes, the qualitative data gave us more insight into what people recorded, how and why these records were kept, as well as giving opportunity to explore the accompanying issues. For example, the comment of the CPN we spoke to in case T06 typified the argument people made for using standard forms she felt that forms: *made it easier, because if I've got some format that I can follow, it's more structured for me. So I went through that format, the documentation, and looking at relevant information [T06]*

This attitude was echoed by the occupational therapist in case F06 in the face to face interviews, as well as the appointee unit manager in case F16.

Those who had experienced dilemmas in the best interests process pined for a structured approach which would sort out their problems for them, and so frequently did mention the value of a standardised pro-forma. However, from the evidence of this study, standardisation did not always link to good practice. The content of a standard form may in itself be limiting. In the example quoted in Report 2, 3.2.1, a paramedic from an ambulance trust described how the form that they use reduces the description of an assessment of mental capacity to a simple *yes/no*, and asks whether:

...lack of capacity is due to a learning disability... and then a tick box for whether you've executed a decision in best interests [T20].

This example not only demonstrates an inaccurate justification for why someone may lack capacity, but also does not give scope for evidencing application of the best interests checklist should a decision be challenged. In contrast with this apparently poor example, the MCA training advisor we spoke to in interview F13b, described a rationale for including a level of detail in his area's standard forms that would ensure that "*nothing was left off the process*" [F13a in Report 3, 7.1]. In this area, he had taken into account guidance from the official solicitor's office about factors that would be taken into account by the judiciary in assessing the appropriateness of best interest decisions. Standard guidance might therefore be more important to achieve, rather than a system that encourages 'box ticking'.

7.2 Sharing records

A theme in both the telephone and face to face interviews was that people often felt aggrieved by how inadequately records were shared. In some instances, interviewees were quite critical about the content of meeting notes; for example the solicitor interviewed in case F04 identified that a social worker's attempt to both chair a meeting AND keep notes had resulted in there being a less than satisfactory set of records (in the solicitor's view). In the detailed case discussed in F09, the voluntary sector representatives described how they received notes from safeguarding meetings, but not from the best interests element of these meetings. Consequently, they did not have a formal record of the process or outcome of that particular decision. The nurse practitioner involved in case F12a, described how additional information from social services meetings would have been of use to the clinical team working with a patient on admission to hospital.

Although the IMCA report is a confidential report for the decision maker only, several people expressed dissatisfaction that they had not received copies of IMCA reports for cases that they had been closely involved with. This could indicate a lack of understanding of the IMCA role, and the status of the IMCA report, but it was also the case that some participants did feel that their own actions were restricted because of this confidentiality. This happened in particular where the role of 'lead decision maker' was not clearly occupied by one person. For instance, in T16, the NHS unit manager was unsure about the proposed outcome of a move from this unit for a man with a learning disability, and implied that he would welcome the opportunity to refer to the IMCA's report as, he stated that he and the IMCA had shared "*some reservations*" about the proposed move [T16, in report 2, 3.2.4]. Similarly, in F06, the occupational therapist was unhappy to have not received an IMCA report, though she acknowledged that this may have been due to the fact that she had not instructed the IMCA.

7.3 Less formal recording

In addition to the formal modes of record keeping, a brief mention should also be made to more informal sharing of information. As we reported in Report 3, Section 7.4, a number of interviewees gave examples of how best interest decisions were recorded in case notes and /or care plans. We gave an example of two respondents who worked with people with profound and multiple learning disabilities, who recorded the range of everyday decisions made for the residents in their planning notes. [F01a and F08]. In another residential setting, the management team of a care home with placements for people with dementia, told how they recorded when everyday decisions were made for someone in a *daily log* [F13a]. We described in Report 3, Section 7.5 how, in another care home setting, the manager had taken steps to encourage front line staff to take responsibility for best interests decision making, and for recording these decisions using a balance sheet which was attached to residents' care plans.

8. The basis of the decision

8.1 Using all the information to make a decision

One of the final questions in the online survey concerned how the actual decision in a best interests process was reached. 215 (56%) of respondents in the online survey said that they had taken into account 'all the information from the process of deciding the person's best interests'. However, another group of respondents said that someone else had been the decision maker and done essentially the same. Therefore, the vast majority of responses were positive, about actually using the information to make a decision, rather than for instance going by past knowledge of a person. Table 22 shows how information was used to make a decision, across different contexts of decision making. Although the difference did not reach statistical significance, nevertheless health care decisions were less frequently made on the basis of using all the information in the best interests process.

Table 22: How the final decision was made in relation to the type of decision in the online survey

	Health care (%)	Personal welfare or social (%)	Property or financial affairs (%)	More than one matter (%)
All the information from the process of deciding the person's best interests was used to make a decision	75	82	86	90
Other responses	25	18	14	10
Total %	100	100	100	100
Total number	67	87	28	76

There were significant differences in how decisions for people with dementia were reached, and also for people with learning disabilities (Report 1, Table 60). Those with dementia were significantly more likely to have all the information from the best interests process taken into account, whereas people with learning disabilities were significantly less likely to have had that information taken into account in making the final decision. It is hard to interpret that finding without looking further at the qualitative data. It could have been, for instance, that people with learning disabilities more frequently had decisions made for them based on previous knowledge which was held by professionals involved in their care, or indeed by their family members.

In the telephone survey, we noted that reaching a best interests decision was not always a straightforward matter; much depended for instance on a clear definition of what the decision was, and what the options were. That clarity in the role of the lead decision maker or the person leading the BI process was key to a good outcome, as discussed above in Section 4.3. Creative thinking, in finding alternative options, was often the way in which successful decisions and outcomes were reached, as discussed in Section 3.5.1 of Report 2. In one case (T10) a woman with learning disabilities had had problems in her residential home, which led to her having to seek an alternative living arrangement. A member of her local community group offered her a spare room to live in while she waited for a longer-term place to become available. Common sense, human solutions helped to solve these potential crisis situations.

Decisions were often based on foreseeing the risks that someone might encounter. As we comment in Section 3.5.2 of Report 2, the telephone survey revealed that many decisions were made with an eye to safety. One of the cases, T14, typified many others in making a decision about the living arrangements of a woman with dementia. In this case the woman had been living with a cousin who had managed her problems by locking her in the house. As the social worker explained:

I suppose it would be in her best interests to go back home, if it could be safe. But because she continually wanders out, sometimes gets lost, it's how safe can you make that. [T14]

The basis of decisions relating to serious medical treatments and interventions were also about balancing risks, and weighing up the risks of the treatment against the risks of not having it. As noted in Report 2, the more serious and life threatening the issue, the more important staff felt it was to follow the MCA wisely and make sure their practices were documented, as we have seen in Section 7 of this report.

Protection of an individual lacking capacity often did entail restrictions. However, as seen in Section 3.5.3 in Report 2, many of our respondents had taken care to consider less restrictive options. A case is mentioned there from the telephone interviews, in which a manager of a day hospital talked through a best interests process relating to monitoring the behaviour of a man with severe challenging behaviour. This case will be given here as an

illustration of how the Mental Capacity Act can lead practitioners, in the words of our interviewee, to 'pause and have time to reflect'.

A man with profound and multiple learning disabilities had lived in institutions nearly all his life, and had no family who were involved with him. He had a long history of self-harming, and the best interests decision only came up because of a review of the care plan that was in place for him; this was a regular review, at least every couple of months. His care plan involved him in being monitored, so that staff had supervision of him 24 hours a day, and wrote down every 15 minutes what he'd been doing, what his mood was and so on. It was felt that this did involve a lot of staff time, and that he hadn't presented any problems for a couple of months. Therefore the decision was simply whether or not this system should be relaxed. The decision was discussed at a regular multi-disciplinary care-planning meeting, where a regular agenda item is about the best interests of the client. The interviewee felt that it was really useful to get a range of multi-disciplinary people around the table, to take time and reflect on possible alternative solutions, activities or decisions for this man. He felt it was a time that they all felt free to challenge each other and ask 'devil's advocate' questions. Although all options were considered in this case, it was decided to stay with the regular monitoring for the moment, with the idea of reviewing that at the next possible opportunity. As the interviewee said, the whole goal was to ensure that this man's care plan gave him the maximum freedom, without having to undergo restrictions of any kind. By regular monitoring, the staff could avoid situations in which they had to be 'reactive' to the problems presented by the man's challenging behaviour. (T37)

Person centred practice generally was another major theme, both in the telephone survey and in the interviews. A strong guide in making a best interests decision was often a consideration of what a person did actually want, or would have wanted, if they had capacity to decide for themselves. However, decisions are often tough. They involve future situations in which all parties have to project forwards and think about what life is going to be like – for instance, with artificial feeding, or in a new home. By definition, the person at the centre of that decision will not have experienced that situation before. Therefore those around him or her have to effectively predict what that person would want, given what they know about him or her. As illustrated in Section 3.5.4 of Report 2, taking into account people's personal preferences was not just about asking the person. The ethos of person-centred planning was

felt to be important in many cases relating to people with learning disabilities, in which those close to the person helped to work out the most important things for a person's life.

A final theme that emerged from the telephone interviews, however, was compromise. In some cases, a complex array of factors had to be balanced against each other, including the individual's likely reactions to a new situation, the practicalities of that situation, cost of services, housing or support, and also the needs of others who were close to the person. Although the MCA relates just to a decision for one person, the reality of people's lives meant that the best interests of one person regularly involved a consideration of those around the person. This dilemma went beyond mere consultation to find out the views of other people. It was about the need to balance the best interests of one person against another. An example was explored above (Section 4.1: T26) in which care was taken to ensure that the decision was taken at the right time for the family as a whole, and considerable sensitivity was displayed towards the need to protect family relationships. In several other cases, the needs of close family carers had to be considered, when working out the best option for people with dementia who were being discharged from hospital. These could be situations where there were multiple dependencies, and so the needs of both parties would be important to consider. What was best for the carer was often a major factor in weighing up the best interests of the person lacking capacity.

8.2 The dilemmas in making best interests decisions

The online survey showed that nearly all respondents thought that the final decision was made extremely well (54.5%: 210) or quite well (41%: 157). Table 69 in Report 1 shows that a mere 4.5% (18) respondents felt that best interests had been decided poorly. This theme was further explored in the interviews, and some additional insights were gained into how best interests were considered, given the reality that weighing up information was not always a straightforward, logical process. In Section 6 of Report 3, we explored what it meant to balance risks and predict what the outcomes would be for an individual lacking capacity. Participants in the interviews reflected on how they themselves had to judge what 'quality of life' would actually mean, and this was particularly critical in situations which were life-threatening or where end-of-life decisions had to be made. What makes a good life for each person is unique to that person, and so the assessment had to be sensitive to that, as a specialist nurse explained:

I think the biggest thing for me is that when I assess patients I have to look at what the

outcome is going to be. And is the outcome going to be that we're going to improve things, or is that we won't improve anything, and that we're not going to change anything? But if I can look at the outcome and know that actually potentially we could improve the patient's comfort and/or quality of life, then yeah, that has a big sort of...it has to be on outcome really. (F11)

We had cases in the interviews where participants discussed in depth how they had carefully observed a person's present state of health and behaviour, in order to really think about the possible future for that person, and what would matter to their quality of life. That included observations for instance of an older person's emotional state, and how fearful they may have been when their physical symptoms were difficult to cope with. These observations could lead nursing staff to conclude that the person's best quality of life would be obtained in a situation where they had other people at hand.

Having looked at those personalised practices, however, we also considered that the overarching considerations lying behind quality of life judgements included the basics of safety, cleanliness, living within one's means and having enough to eat. If people lacking capacity chose options which put them at risk of losing that first, basic level of human dignity, then their decisions were over-written by the best interests decision, and the MCA clearly supports that path. Nevertheless, there were some fundamental tensions for professionals at the heart of these decisions, particularly perhaps for social care staff who were driven by understandings of autonomy and choice. There were times that staff drew back from considering a best interests decision, according to our respondents, when they felt worried that they would interfere with the human rights of the person to decide things for themselves.

One of the cases which brought to light clearly some of these dilemmas was F14, which concerned a woman who was dying of heart disease. The GP had listened to the woman herself, and assumed that she had a right to say for herself what she wanted at the end of her life. Although she did have certain rights, however, the staff in the care home saw that she lacked capacity to make an informed decision about her own death, since she simply did not take into account that she was dying. Making a best interests decision, and using the Mental Capacity Act wisely, was felt here to be both a clear pathway to ensuring the patient had a peaceful end to her life, but also it was a way of protecting the nursing staff, who would be able to know that their care practices were endorsed and supported.

8.3 What helped, and what would have helped, in making best interests decisions?

The online survey included a question about the information that had been used in making a best interests decision. 207 respondents stated that additional information or guidance was used to help with the best-interests decision-making process, and completed a free text box with details of the type of information or guidance they used. These responses can be represented in the categories shown in Table 23 below.

Table 23: Sources of information and guidance used by participants in online survey

Source of additional information	n	%
Information / advice from other professionals	45	19.1
MCA Code of Practice	38	16.2
MCA / MCA Guidance	38	16.2
Local Guidance – NHS / Trust	26	11.1
DOLS Code of Practice	17	7.2
Local capacity assessment tool	16	6.8
Local Guidance – other	9	3.8
Best interests checklist	9	3.8
Other professional guidance	6	2.6
Previous contact with person and/or their family / friends	6	2.6
Previous Training	4	1.7
Mental Health Act Code of Practice	2	0.9
Other	19	8.1
Total	235*	100

* This total exceeds the number of respondents as some referred to more than one form of information or guidance.

It would be thought that those who indicated that they had consulted guidance would have had the ‘best practice’; however, there did not appear to be any evidence that that was the case in the online survey. People who had said the person for whom the decision was made *did* have capacity were just as likely to have consulted guidance as anyone else.

We can conclude therefore that much depends on the quality of the guidance and its relevance to the case in hand. More detail emerged from the later stages of the research about what mattered to individual practitioners. More than one person mentioned the value of having a brief guide, such as the ‘five points’ about assessing capacity; others however felt that guidance only came to life when it related to ongoing practice, which gave colour to what was previously felt to be quite ‘grey’. Participants very much valued the structure given by the MCA Code of Practice, but of course no guidance will answer immediately the question

one has in mind from a particular case. In fact, the case study examples were felt to be sometimes rather frustrating, since they did not give an 'answer'. Practitioners hankered after the simplicity and clarity of a tool that would simply tell them what to do. However, more considered responses recognised that such a tool would by definition not cover some of the complexities they faced in real life situations.

There was plenty of discussion within the interviews about what would help, and the emphasis here was on training, support and guidance that would be specific and relevant to particular professions. In particular, medical staff in the telephone survey spoke of the irrelevance of some of the issues and cases mentioned from a social care perspective, and ambulance staff in particular had a need for practical support that was relevant to the urgent cases they faced.

Discussion about the types of training needed is included both in Reports 2 and 3, and includes a strong emphasis on interactive training, which allows people to participate and bring their own issues to the discussion. Ideas for training included simulated role play, as well as briefing sessions held within care homes. People also reflected on how much they needed to keep 'up to date' with new ideas and cases, as they emerged, and that training always needed to be updated, or backed up with written or online information. Some spoke of the 'trickle' effect, as they learnt more about good practice from a combination of their own practice, training and updates to that training.

However much written information and training were available, participants in the telephone survey tended to say that they got the most useful support from colleagues within their trusts or organisations, and particularly from local Mental Capacity 'leads' or advisors. In one area, almost every participant spoke of the value of being able to consult with MCA advisors, who were considered knowledgeable and flexible in their response. It seemed important that this central support role was not just associated with one aspect of social care, but was available to different professionals across health and social care sectors. We concluded that ongoing support was vital.

9 Outcomes

9.1 Decision, but no action

Best interests processes are about outcomes, and not simply about decisions. As we have seen above (Section 8.1), the majority of respondents in the online survey felt that the decision had been made extremely well, or quite well. However, in the telephone survey, we also reviewed a range of outcomes (Section 3.7.1 of Report 2), which fell into various categories. Urgent treatment decisions generally resulted in the life-saving treatment being given in every case, while discharge decisions more often resulted in people moving to residential or care homes (19 cases), compared with eight people who were discharged back home. Financial decisions in general (6 out of 8) resulted in arrangements being made to keep a person's finances or affairs safe, and in the ten cases about medical procedures, five ended up with the person not having the procedure. Three cases had resulted in successful treatment being received, while two had not yet been actioned.

One of the points we noticed here was that ten cases involved a decision that had not yet been put into action. In six of the cases relating to change of accommodation, for instance, a placement had not been found in a suitable care home, or the funding was not yet available. Two medical decisions as well had not yet been put into action, and both had been delayed by a failure of professionals to work together in an efficient way. For instance, in one case described to us by a volunteer for a disability charity, the decision to have an operation had not been taken any further, since no medical practitioner had been involved in the discussion. Finally, we noted some cases in which an outcome could only be achieved by the person lacking capacity actually complying with the decision; that included for instance the case in which a person was refusing to have a bath, or another man who refused to brush their teeth. Different factors, then, can influence the outcome, some of which are 'intrinsic' to the process of best interests decision making, and others of which are about lack of resources in the outside world. In order to move towards a successful conclusion, an implementation plan needed to be included, as well as a simple decision. In some cases followed up at the interview stage, successful implementation was very much part of the whole process – including for instance, in F09, Derek's story in Appendix A of Report 3, where Derek and his support staff had been fully involved in finding an appropriate residential placement for Derek, ensuring that he accepted it, and planning for his future with

all parties concerned. Despite that detailed level of planning, however, his future was still slightly uncertain at the time of the interviews, since funding had not finally been released to enable him to have 24 hour support. Local authority cut-backs and eligibility criteria could still trump the best interests of a person requiring support.

In the interview stage, we noted in Section 8 of Report 3 that the finite availability of resources to provide care in a person's own home could also be influential. In most cases, those real-world restrictions were known about, and so decision makers would have taken them on board before suggesting what might be the best option. As in the telephone survey, we also noted that factors relating to a person's health condition would be relevant to implementing a medical decision, but all these could be confounded by the barriers caused by factors about the actual best interests process. It is perhaps those which are of greatest note here, since they are matters that could be improved in relation to best interests decision making, namely poor communication, lack of information sharing and hostilities between professions.

9.2 Ways to ensure a good outcome

A successful outcome of a best interests process is not just about 'job done', but must be about the successful life experiences that are enjoyed by the person for whom the decision was made. In many cases, however, our participants did not actually know much about the detail of the outcome, from the point of view of the client or patient. The few family members or friends we spoke with differed sharply in that respect, since they were fully aware of exactly how their family member was living, the things they were enjoying and the factors not working in their lives. In many cases, the decision maker was a few steps removed from the day-to-day life of the individual lacking capacity. As we noted in Report 2, Section 3.7.3, it was therefore essential to have some kind of review system in place.

Medical practitioners who had been involved in a best interests process only kept in touch with patients who remained 'their patients'; in other words, those who had decided not to have a particular procedure were rather lost from view. By contrast, social care practitioners generally did have review systems in place, and these were built into the process. As the day hospital manager in T37 said, who had been involved in a best interests decision about monitoring the behaviour of a man with severe challenging behaviour:

If you know that you are going to be, in three months' time, going over the same issues again. It sort of – again, it's human nature isn't it; gives you a kick up the backside, basically, to remember, oh, I must remember that..[T37]

At the interview stage, we explored further some of the systems of support that needed to be put in place, to ensure a continued successful outcome. Some of the funding problems, for instance, were not inevitable. The man who was moving out of a NHS residential facility was found to possess funds of his own, which had been looked after by a corporate deputy. He was therefore able to use some of his own funding to supply the support he needed. As we also noted in Section 8.2 of Report 3, medical decisions and procedures were not an end point in themselves, and often implied changes in staff practices, to give ongoing appropriate care to the client or patient. The specialist nurse in the PEG tube cases commented that staff training was a key to ensuring success. All these factors therefore needed to be built into the best interests process, and provided ways of moving from decision to successful outcome.

A successful outcome was construed by participants in different ways, and often by a combination of three different sets of factors. The first concern was to please the person for whom the decision was made, and so success in that regard meant that the person was happy. Pursuing that goal meant ensuring that the important things that mattered to an individual were in place, such as having enough company, being able to spend one's money for holidays, or being able to get out in the garden.

Secondly, success was about the degree of protection afforded to the person lacking capacity. Many of the best interests processes described in this report revolved around safeguarding and risks, and so achieving 'safety' was of course a measure of success. In particular, the delicate balance between safety and independence was said to be a major achievement:

I think from our point of view yes. It enabled this lad to remain living independently and safely. That looked after both the short, medium and longer term goals. But we were also aware of the ability to change his mind and be involved in future decisions about what he chose to spend his finances on. [T15]

Finally, protection of staff was felt to also be an important outcome of a successful best interests process. The Mental Capacity Act was able in many cases to ensure that staff were working in a defined and agreed way to protect individuals, sometimes from themselves, and sometimes from procedures or treatments that would not have helped their eventual wellbeing. Taking these decisions was often stressful, but perhaps not as stressful as providing day-to-day care for someone whose best interests were undecided. The Mental Capacity Act was welcomed by most of our participants, who particularly felt that it had given greater clarity to a confused area of law and practice. They particularly spoke about patient rights, about the flexible approach to capacity enshrined in the Act, and about the protection given by the MCA both to clients and to staff. A learning disability psychologist spoke for many when she said:

I think it's made a huge difference. It's provided a clear structure. And it has a good balance between opposing situations. So that you get less neglect, but you also get the person's voice heard, but you also get the system's voice heard where there's a difference of opinion. I think it is good. I've certainly found that I think that services are much more contained and less impulsive as a result of the act. (T17)

9.3 How are they now?

We will conclude this section on an upbeat note, with an overview of some of the successful factors in people's lives, following best interests processes. At the time of our second interview with the specialist feeding nurse, the young woman in F01 was still alive and enjoying her food, as well as her relationships with her family and with support staff; in the other artificial feeding case, the man had had his operation successfully, and had become more alert and responsive. The older woman with mental health issues who had to be discharged from hospital in F04 had moved from the home where she was unhappy, and her husband had selected a more suitable and quieter home, where he could still visit regularly. In F03, where the mother and son were unable to manage their property and affairs, the second solicitor at least had established a good relationship with the mother. Their assets had been released, and their debts paid off, so that they could live together with some dignity. The older woman in F16 had also gained benefit from having access to her own money, and was able to buy new clothes that she liked. The solicitor in F02 had also described her own family member, who had dementia. He was living still in a care home, but she visited him regularly, and her decision to keep his belongings in store had paid off.

In F06, the elderly woman with dementia had not yet moved, and so it was not quite clear which home she would be able to go to, while in F12, as is explored below, 'Lily' had in fact died while the discussion about her care home continued. Nevertheless, the social worker in this case argued that Lily was happier dying in a familiar environment, and would have probably not benefited in the end from a discharge from the hospital.

The man with learning disabilities in F08 had moved out into a community house, with good support, by using his own money initially to provide one-one support. He was quite settled into his new home, by means of a careful transition plan implemented by his former support team. Similarly, the man in F07 had moved into his own flat, with a deputy managing his bills and rent. F09, also, had involved much careful planning and preparation for the young man with learning disabilities, Derek. However, at the time of the interviews, some six months after the original decision, he had still not moved, as the house was still being built. The woman in F13 was enjoying a greater degree of social contact, since she had started to wash and bath more regularly, and in F15, the young woman was back from Thailand, and having to save her money to pay off her debt.

For all these people, the best interests decision had produced a safer life, and a happy solution to the particular issue or risk they faced. However, the success of this outcome was always due to people and relationships. Even for the woman who had terminal heart disease, good relationships with familiar nursing staff were important in her remaining days, and these relationships improved because of the security of knowing that decisions had been made about letting her die naturally. A best interests process therefore never existed purely as a ruling about someone's life; the Mental Capacity Act both supports and protects *individuals*, but the lives of these people were set in the context of social relationships, both with friends, family and supporters.

10. Overviews and trends

Thus far, this report has explored the data from BIDS on a chronological basis, following the best interests process from the assessment of capacity through to the outcome, and analysing the evidence for differentiated practice through that journey. Section 10 now presents the same analysis, but with a cross-sectional cut through the data, in order to summarise what trends we noticed first of all in the major sectors for best interests decisions (health, social care and property and affairs), and secondly what was noticeable about practice for groups of people with different impairments. Following Section 10, we will then draw some overall conclusions and finish with our recommendations for practice.

10.1 Trends in best interests decisions in different sectors

10.1.1 Best interests decisions about medical treatment

Best interests decisions about health care accounted for 184 (48%) of the cases reported in the online survey. However, as noted in Section 2.1 of this report, that does not constitute a claim about medical treatments as the prime context for best interests processes. In fact, it turned out that less than half of those cases were about consent to serious physical health care treatment; a large proportion of our sample of health cases were related to applications for DOLS, and others in this category probably included some of the cases regarding discharge from hospital. In this section, we will summarise the patterns and trends that occurred particularly in cases relating to actual treatments.

What can be said about the types of medical decisions that were considered under the MCA? We know from the online survey that this category covers everything from decisions about consent relating to life-sustaining treatment (31 of these were reported online) to decisions regarding psychiatric treatment (18 online cases), and that a large proportion of them were not about consent, but about other matters relating to health. In the telephone survey, health care decisions accounted for 21 of the 68 decisions discussed, although it should be noted that the discrepancy at this stage, compared with the online survey, was at least partly accounted for by the fact that the cases were categorised post hoc by the research team; only those matters relating to health treatments were counted as 'health', while issues to do with protection or change of accommodation were counted as personal

welfare decisions. Finally, six of the 25 cases followed up in interviews related to medical treatment of some description, or were about health matters.

Despite being the most common type of best interests decision reported in the online survey, health care decisions were not so dominant for people with dementia as they were for other groups. Regarding the professionals involved, health care decisions were far more likely to be made by health care professionals, and also (compared with other types of decisions) by those who were part of a multi-disciplinary team. However, looking at just the medical clinicians who answered the survey, they were equally split between being 'joint decision makers' and 'part of a team'. Therefore, it can be assumed that decisions about medical treatment, which were led by clinicians, were less likely than other health care decisions (such as change of accommodation) to be taken within a multi-disciplinary team. Further, it was noted in the telephone survey that deterioration of health could be the 'trigger' for a best interests decision which involved social or welfare matters, and particularly that a period in hospital could lead to questions relating to a person's future accommodation and/or their financial situation. Therefore, health matters may have been the 'lead in' to considering the MCA for a wide range of issues.

Assessment of capacity

Just over half of the health care decisions reported in the online survey were based on an assessment of capacity that took place on the same day as the decision. Although that was a similar pattern for other types of decisions, the trend to assess capacity just before the decision was made was slightly greater for health than for other decision types. In the telephone survey, we noted a common tendency to assess capacity for health related decisions by an implied assessment of the 'level' of someone's impairment. There were several cases in which assumptions had been made about the patient lacking capacity, and it is important that this did not just occur with people with learning disabilities or profound, ongoing needs. We noted also that urgent medical decisions understandably had to be associated with rather summary assessments of capacity, and that paramedics in particular therefore worried about the assumptions they had to make about assessing capacity, even when they had good training and guidance.

A few (36) respondents in the online survey reported that a best interests process had been carried out, despite the person actually having capacity to make that decision. Although this

number is too small to assume statistical significance, nevertheless over half of those 36 cases were about health care matters. Further, over half of the assessments of capacity based on a person's 'disability, history, diagnosis, or illness' took place in health care contexts. Much of this may simply, of course, relate to the fact that more health care matters were reported in the online survey than other matters. However, impairment related assumptions about capacity in health care cases were reiterated in the telephone survey, for instance by this service manager from a social care NHS trust (T28):

He didn't communicate, he had some very mild, challenging behaviour, he would find it difficult being – he also had autism, so he would find it difficult being with strangers. So everybody that was there felt that he lacked the capacity. (T 28)

In other words, the difficulties of making a well informed decision about one's own health often tipped the balance in favour of an 'assumption' of incapacity. Nevertheless, in some cases, it was appreciated that capacity was both fluctuating and often influenced by the very medical factors that were at issue in the best interests decision. In other words, being ill can influence someone's ability to make a decision for him or herself. That was particularly so in cases related to mental health problems, where people's mood or state of ill health were seen to affect (temporarily) their ability to make a decision. Crucially, that was used as an argument to assess a person as lacking capacity about medical treatment, including life-saving treatment, and also about other matters such as deciding where to live.

Process of best interests decision making

One of the most significant trends about health care decision making related to the process by which decisions were made, and this trend threaded through all the stages of the research. In the online survey, health care decisions (compared with other types) were more frequently made at a single meeting, or at meeting(s) that did not involve the person lacking capacity. In the telephone survey, we saw further how 10 of the 21 cases classified as 'health care' took place through single or multiple multi-disciplinary meetings. However, these were not always decisive, since the medical consultant was not always present at the best interests meeting itself. It follows that there were a large number of cases in which other professionals and family members had meetings to discuss a best interests decision about health care, without either the decision maker or the person for whom the decision was being made.

Bizarre though this situation may seem to be, nevertheless the interviews covered some cases in which very effective processes seemed to have taken place, regarding health care decisions. In particular, the decisions about artificial feeding were carried out according to a model in which the senior health consultant both discussed cases in regular multi-disciplinary meetings, and in one case, attended a meeting with parents and home care staff of a woman with profound and multiple learning disabilities. Although the consultant was the ultimate decision maker, this multi-stage process appeared to both our interviewees to be a very fair, thorough and well-informed process.

When asked to consider generic issues about the implementation of the MCA, many of our respondents spoke disparagingly about the lack of awareness of medical personnel; nevertheless the cases described in the research revealed some good practice. There were only a handful of cases in which a medical practitioner had perhaps played a problematic role. For instance, the case about end-of-life care in the interviews involved a GP who had unilaterally made a statement that a woman *did have capacity* to decide that she should always be resuscitated. There was very little communication with those providing care for the woman, let alone consultation or an attempt to gain a broader view of capacity. Another case in the telephone interviews involved a decision for a man with challenging behaviour and learning disabilities to have a blood test, and this had been overruled by a medical consultant, who had not even taken part in the best interests process. Finally, the consultant who took part in the telephone survey spoke of the general lack of engagement with the MCA amongst senior medical practitioners, who did not always see it as their role to look at issues beyond the 'best treatment' to manage the illness or symptoms of a patient.

Conversely, then, it is worth remembering that in about half of the health cases in the telephone survey, and at least 3 of the 6 medical cases in the interviews, medical practitioners had taken pains to consider the patient holistically. That included taking into account non-physical aspects of their health, relationships, preferences, and understanding. They had done this not only by direct communication with the patient, but also through joint working with other practitioners, such as occupational therapists, specialist nurses, home care staff and speech therapists. In all those cases, medical practitioners, other professionals such as nurses, residential care staff and family members both talked together informally, and tended to meet in a formal best interests meeting. There were also cases

discussed in which a regular team meeting was held amongst professionals in a particular setting, such as a hospital, and issues relating to each patient's best interests could be returned to on a regular basis.

Information and record keeping

Some of the key features of health related cases were the availability of accurate medical information, the way in which that was communicated to all involved, and also the accuracy of record keeping. In Section 4.3.4 of this report, a medical decision was explored from the interview stage, in which home care staff particularly valued the clear information given by the consultant as well as the specialist nurse, relating to artificial feeding. That information had helped to shape their own opinions, and ultimately, the decision that was made. In Section 5.1, we also mentioned instances in which information was made accessible for the person lacking capacity and for those around the person. That included information about pregnancy, as well as the implications of intrusive operations. We do not know exactly how successful these strategies were, from the point of view of the person lacking capacity. However, they are certainly worth exploring further. In the focus group stage of this project, which is reported elsewhere, staff in a neurological hospital had produced a user-friendly booklet to explain PEG tube insertion, and the implications it had. However, those we interviewed had no access to that booklet.

Regarding the records kept by professionals, we found in the online survey that decisions about health care were significantly more likely to be recorded in a 'detailed note', as compared with other decisions relating to personal welfare or financial matters, which more frequently used standardised forms. In Section 7.1 above, we have however highlighted that professionals frequently praised the value of standardised procedures and forms, since the pro-forma often guided their practice and reassured them that they were covering the essential elements of a best interests process. In one area where standard pro-formas were used across health and social care, they were seen as valuable ways to ensure transparency between all the professionals involved with a case. By contrast, where a medical practitioner made a unilateral decision and simply recorded it in the patient's record, as happened in the end-of-life case in the interviews, it was difficult for others to understand how that decision was reached and what it might imply.

Consulting and involving the person lacking capacity and the family

The online survey revealed that in 48 (13%) of the cases, the respondent felt that the person's wishes, views or feelings, or their beliefs and values, were *not* taken into account in the final decision. Half of those cases (26; 54%) were about health care. In order to discover and consider the person's wishes of course, it will be essential for health care professionals to have some system of consulting, both with the person him or herself, but also with relatives. It might be thought that this is difficult to achieve in urgent medical decisions, but in fact further analysis showed (Report 1, Section 10) that these cases in which the patient's views had not been considered were not significantly correlated with the urgency of the timescale. Although this only related to a small proportion of cases, therefore, there is evidence that medical practitioners still need to find ways to involve and consult, before making their final decision.

In the telephone survey and in the interviews, we saw ways in which that consultation could happen effectively. For instance, in F25 the consultant was guided by the MCA lead in the hospital, and was able to make a serious and relatively urgent decision about medical treatment for a woman with pleural effusion, based on a conversation around the bedside with those who knew here best. Although other less urgent decisions did involve meetings with families and with the person lacking capacity, meetings were clearly not the only answer. It is important to emphasise that informal contact, using third parties to make contact, and certainly making effective use of written information can all be effective ways of finding out more about the person's wishes, views or values.

In other cases, however, the family's judgment of the situation was part of the 'problem' that had led to the best interests process itself. That was so in the issue relating to contraception for a woman with learning disabilities, and in the case of the man who needed to leave the family home for psychiatric treatment. In both those cases, the medical judgment of experts conflicted with the views of family members, and so, following efforts to persuade the family, finally a decision was made which was then communicated to the family. Involvement in medical decisions, then, could be described as a continuum from consultation through persuasion to the requirement for compliance. At one extreme, family members' views would sway the whole decision, while at the other extreme, their views would be overruled and negated.

Outcomes in health related decisions

Medical decisions were nearly always driven by a desire to preserve life. This was neatly summed up by the consultant who spoke with us in T44:

I think, to be honest, once you're admitted and in a hospital bed, the entire system is geared to can we get you better? And that's what they do. [T44]

The judgment of the medical practitioner him/herself was thus a key to the process, since it was their knowledge that underpinned the whole decision. It was hard for medical practitioners to admit that their own best judgment of a person's medical interests had to be weighed against other factors in a person's life.

Medical practitioners in our telephone interviews were involved in many other decisions besides medical ones, for instance those relating to discharge from hospital, and these will be discussed below. However, those decisions that were actually about medical treatment were, in the end, the responsibility of the senior medical practitioner or GP involved in the case. The extent to which that person was able to provide information to others, listen to other views, and organise a process that genuinely took into account a range of factors was vitally important in these decision processes.

It is very likely, as our respondents often said, that medical practitioners are still not fully informed about their responsibilities under the MCA, and this was hinted at in Case 49, where a consultant had made a unilateral decision against a blood test, having failed to take into account the outcome of a best interests process. On the whole, however, our telephone survey challenged the stereotype of unapproachable and authoritative senior medical practitioners who rely entirely on their own medical expertise. As mentioned above, the research design favoured those cases where practitioners felt confident and positive about the best interests process they described. Nevertheless, these cases give indications of a changing tide towards medical practice which:

- Involves a range of other professionals in a multi-disciplinary team model;

- Provides information to inform decisions, including attempts to make that information accessible to all parties involved;
- Takes into account social and personal life issues, and weighs them up against the strictly medical best interests of a patient.

10.1.2 Social care decisions

Ninety-three (24%) of cases in the online survey were about social care or personal welfare, and 38 (41%) of those were about a change in accommodation, with a further 15 (16%) related to adult safeguarding. As argued in Section 2.2 above, there were proportionally a greater number of cases about a discharge from hospital or a change in accommodation in the telephone survey and in the interviews. Therefore, it would seem that change of accommodation represents the largest category of decisions that are classed as 'serious matters' under the MCA.

It should also be noted that only very small numbers of respondents answered the online survey in relation to an everyday issue, such as what to eat (6; 6.5% of social care cases) or about intimate personal care issues (5; 5.5%), or indeed about 'significant social care events' such as holidays (3; 3%). As noted earlier, we have reason to believe that respondents to the online survey tended to pick serious or life-changing matters for their best interests case. It may also have been the case that more minor or mundane decisions were not always seen as matters for the MCA. Finally, the other category one might expect to be included here was that of care reviews, where decisions were being made about someone's support plan or personal budget. There were only 5 (5.5%) of cases in that category in the online survey. Since we had targeted the online survey both at health trusts and at local authority staff, it would have been expected that social care managers would have responded with regard to care planning. Care reviews are also meant to be undertaken when there has been a change of accommodation. Thus the absence in that case might well imply that the Act is not being so well used for that purpose.

With respect to more minor, everyday decisions, we made deliberate attempts to capture more examples at later stages of the research, by attending and speaking at events where we could recruit care home staff, and also by offers of visits to supply training and support to care homes. Therefore, the profile of social care cases appeared to grow over the course of the research, with 37 of 68 telephone interviews relating to social care, and 15 of 25 of the

interview cases relating to social care. However, of the latter, 10 were specifically about change of accommodation or discharge from hospital; it should also be noted that the classifications in these cases were made post hoc by the research team, according to what the participant told us, rather than allowing the participant to classify the case. Despite these provisos, the overall picture we have of social care decisions is that they occurred most frequently in cases relating to change of accommodation or safeguarding. There was a general theme of safety and protection in most of the decisions, including those relating to accommodation. By contrast, the MCA appears to be under-used in matters relating to care planning, and also in everyday, routine matters. However, this under-reporting could simply imply a lack of confidence or willingness to take part in the research.

Assessment of capacity

The vast majority of cases about discharge from hospital were ones in which a person's capacity could be assessed over the period of time that they were in hospital. Nevertheless, in general it appears from Section 3.2 above that personal welfare or social care matters were just as likely to be 'urgent' as any other matter. However, those decisions relating to change of accommodation, were often based on a lengthy assessment of capacity. In those cases, the telephone and interview data in particular revealed how professionals responsible for social care decisions were often sensitive to the fluctuating nature of capacity and the extent to which a person could actually make a decision for themselves.

An assessment of capacity about change of accommodation was often linked to the perception of risk involved, and the need for a 'safe' outcome. It was noted, for instance, in the telephone survey, that the majority of these cases resulted in the person being admitted to some kind of care home. It was also here that the argument about 'insight' was most common: lack of capacity equated to the fact that a person could not understand or admit to their own care needs. That reasoning then frequently led to the decision being made that they would need to live in a more protected environment.

The generic category of 'personal welfare' covered a range of different sub-types of best interests decisions, and also involved a range of different professionals, from social care managers to occupational therapists, care and nursing home staff, discharge nurses, and in fact also medical practitioners. However, it was sometimes said in the interviews that good practice in assessing capacity would be to defer to a social care professional, who

understood better the issues involved. Practice did vary, and we noted in the telephone survey a tendency amongst residential home staff to assume that capacity had to be assessed by an external, more senior professional who would have the authority to assess capacity. In some cases, many sources of expertise were mentioned, all of which had contributed towards assessing someone as lacking capacity.

Social care professionals were the most likely people to be involved in 'advance' capacity assessments for certain groups; for instance, they were likely to be called in to assess capacity in care homes for people with PMLD, whereas it was more likely that a medical practitioner would be called in to assess capacity for someone with dementia. All of this could create a rather 'static' concept of overall deficiencies in capacity, rather than a decision-specific assessment. Nevertheless, as seen in the interviews, personal welfare decisions were also informed by some very sensitive practice in assessing capacity. That included cases in which everyday matters of personal care were involved, where home staff took care to ensure that the resident's autonomy and dignity were not compromised. It was here, though, that perhaps there was the greatest difficulty experienced in understanding the decision specific nature of a capacity assessment, and the support of regional or local MCA advisors was invaluable to care home staff.

Process of best interests decision making

There were some significant findings from the online survey about the typical patterns in social care decisions. Compared with 31% of health care decisions, over half of all decisions regarding personal welfare or social matters, property or financial matters, and more than one matter, involved a series of meetings between the decision-maker, the person and usually others who knew the person. As we have commented in Section 4.3 of this report, this preference for a series of meetings in social care decisions was possibly linked both to the culture amongst social services staff, but also to the need to involve the person maximally, and to deal with any conflicts so that a consensus was reached. That last point was evident from the telephone survey, where interviewees from social care backgrounds typically denied their sole responsibility as 'decision maker' and claimed that decisions were always made jointly. It should be recalled that social welfare decisions involved health care professionals almost as frequently as social care professionals. However, as the more detailed analysis of the professional roles of online respondents showed, many of these were

in professions allied to medicine, such as occupational therapy, and others would have been those responsible for residential services but employed by the NHS.

The activities to prepare for a best interests meeting were of paramount importance in social care cases, as seen both in the telephone survey and in the interviews. It was in cases relating to protection and risk, for instance, where respondents reported the efforts they had exerted to contact a wide range of people. They had also involved IMCAs where necessary, and as explored in Section 6.2 above, there were a few cases where IMCAs had been appointed because of the conflict experienced with family or friends. Social care professionals in particular were very clear about their duty to keep the interests, and also the voice, of the client at the heart of decision making. Other respondents (e.g. solicitors) in the interviews sometimes complained that social services professionals erred on the side of client autonomy. However, respondents who were leading or closely involved with social care decisions often cast themselves in the role of 'advocate', and explained how they had fought for the rights of the person lacking capacity. In social care decisions relating to people with learning disabilities, person-centred planning was also mentioned in three cases in the telephone survey, as a device to help include the views and wishes of the person lacking capacity.

Section 4.3 of this report explored in further depth some of the 'structures' or patterns which professionals drew on in making best interests decisions. Typical of social care cases was the multi-disciplinary approach, with a string of meetings, as we have seen. Also typical of these cases was a high degree of professionalism in chairing meetings, leading the best interests process in general, and making a clear definition of the decisions to be made. It was principally in social care where the 'main' decision was differentiated from a set of 'sub decisions'. That pattern was particularly important where it enabled the person lacking capacity to be consulted and more fully involved in making those sub-decisions, for instance about which care home they would move to, or even about the decorations or furniture.

Information and record keeping

The online survey revealed that there was a significant difference in how best interest decisions were recorded. Decisions about healthcare matters were more frequently recorded in a detailed note about the process and outcome, whereas decisions regarding property or financial affairs, or about personal welfare or social matters were more frequently recorded

on standardised forms or pro-forma. The benefits of pro-formas were almost universally mentioned in this type of decision-making, with respondents in the telephone survey speaking of the value of pro-formas in structuring and guiding both the process of assessment of capacity, and the best interests decision itself.

Social care decision making however also typically involved meetings, as we have seen, and a characteristic of those meetings was that minutes were taken formally, as claimed by some of the respondents in the telephone survey. However records were kept, the most important factor was that they were shared between all parties. Successful outcomes in best interests social care decisions were often attributed to good communication. For instance, a case was followed up in detail at the interview stage where forms, records and minutes were passed between safeguarding meetings, care home staff and manager, and a psychologist involved in the case. This good communication of written records enabled 'work streams' to be set in motion between meetings, so that the whole process appeared very well structured.

Routine, everyday matters which became the focus of best interests decisions were harder to record. Care home managers in the interviews were aware of the need to record these decisions, but were anxious to find a time-effective and convenient way for their staff to carry out this type of record keeping, so that it did not take over from the care work itself.

Involving other people in the best interests process

Just as in health care decision making, social care matters were often successfully resolved by a process that consulted as many people as possible, and where information was shared. However, the role of family members did vary according to the type of decision being made. For instance, despite the 'person centred' tendency noted within social care decisions, a feature that characterised at least some best interests processes in this category was the need to balance one person's interests with another's. For instance, where an older person was being discharged from hospital, the needs of family carers had to be weighed up along with those of the person lacking capacity. A few cases followed up in interviews were about very difficult situations, where a relative could no longer cope, and yet was intensely emotionally involved in the best interests of the person lacking capacity. Handling these matters sensitively was considered to be of paramount importance, as was also the necessity to find 'creative' solutions. One tactic was often to engage the relative in choosing a care home for the person lacking capacity, and to ensure that their relative was situated

close to home and would be able to have regular visits. It should be mentioned here, however, that those cases in the telephone survey which were described by a relative or friend of the person lacking capacity revealed a somewhat different picture. Family members or friends said that they had felt left out of decisions about where their relative moved, and were not consulted. However, equally, they were the people who were left to pick up any problems afterwards, and they sometimes instigated courses of action to ensure that their relative would be content in their new environment.

Social care matters relating to people with learning disabilities in particular were far more likely to involve family members more centrally in the decision making process than other groups. For instance, people moving into independent living accommodation sometimes had parents or other family members whose concerns had triggered the best interests process in the first place. In the cases we explored, at least, the views of family members were always central to the decision making process. For instance, a person moving out of secure accommodation was felt by his parents to be unsafe because of lack of capacity in financial matters; the professionals involved therefore assessed and agreed with the parents, and although the man did move into his own flat, his finances and bills were taken out of his control.

Social care best interests decisions could also, however, be triggered by mistrust of family members, who were sometimes felt to be abusing the person lacking capacity. A few cases in the telephone survey and in the interviews were triggered by the suspicion that a relative was taking money from the person lacking capacity, and in other cases, relatives were either construed as 'too close' and protective, or acting against the physical best interests of the person. In these cases, social care decisions very clearly favoured the person's own best interests, and the rights and views of family members or other third parties were side lined. This was achieved for instance by holding meetings to make the decision to which family were not invited, and communicating the decision afterwards to family members. However, those who discussed these cases felt strongly that diplomacy and sensitivity had to be exercised. Where a family member's views had been overridden, there may still have been a relationship to maintain, and so social care best interests decisions had to be very carefully implemented. There was always a concern to persuade and involve people as far as possible, in order to win over all significant parties to what was considered to be in the best interests of the person lacking capacity.

Outcomes in social care decisions

As noted in Section 9 of this report, it is not only important to carry out an effective process. The best interests decision also needs to be put into action. In those cases relating to change of accommodation, or discharge from hospital, one of the key factors that impinged on the outcome was the availability of a care home and/or the amount of funding available. Even where a person was proposing to move from one type of accommodation to another, their eligibility for increased funding had to be taken into account, as was seen in the interviews. Financial cuts, or restricted eligibility criteria, could delay or change the outcome of a best interests process. Inevitably, those factors often had to be taken into account. For instance, it was said that the amount of care someone could have in their own home was restricted, and so those needing 24 hour care had to move into a care home. The best interests of the person lacking capacity have to be seen in the wider context of what is available and what was possible.

Since many of the social care decisions discussed in this report related broadly to safety and protection, a successful outcome was often felt to be an increase in protection of the person lacking capacity. People were felt to be vulnerable since they could no longer manage on their own, or indeed because they were refusing elements of support or care, including self-care. Some individuals additionally were engaging in particular behaviours which put themselves at risk, and so were felt to need an increased degree of protection and support. In general terms, then, the outcome of this type of best interests process was that the person lacking capacity had to comply with the decision about their own best interests. As we have explored above, some participants in the interviews felt keenly the tension between protecting a person and ensuring their autonomy, and this was possibly a particular problem in the understanding of home care staff. Despite their reservations, however, care staff were often left with the task of persuading the person to comply, since otherwise the best interests decision could not successfully be implemented. Persuasion was sometimes necessary in larger decisions about moves or protection, but perhaps more often in cases relating to refusal of the necessary care and support. Effectively, the MCA gave care staff the right, with proper process and consultation, to enforce what they felt was in their client's best interests. The tensions in this area of social care decision making require further exploration, particularly at the level of delivery of everyday care and support.

10.1.3 Property and affairs decisions

Decisions relating to someone's property or affairs accounted for only 7% (28) of the cases reported in the online survey, although the cases relating to 'more than one matter' may well have included financial or property issues. Although the numbers were small, it appeared that most of the decisions falling into this category were about someone's financial affairs in general. However, compared with other people, those with learning disabilities seemed to have a wider range of property and affairs decisions made on their behalf. That would accord with the common view that people with learning disabilities may not be able to handle their own financial affairs, and would need others to manage these things for them.

Since we were aware of a shortfall in this area, deliberate efforts were made to include solicitors and corporate deputies in subsequent stages of the research, and so, although the numbers were still small (N=4), we were able to follow up several participants in each of these settings, and to discuss more than one case with each setting.

Assessment of capacity

Those taking responsibility as a result of property and affairs decisions were seldom the people who had assessed the capacity of the person. For instance, in the telephone survey, where the decision was about who should manage a person's finances, capacity was generally assessed by a 'clinician' or a mental health or medical professional. Although this accounted for only nine cases, the trend was also reflected in the interviews, including those with corporate deputies. Assessing someone's ability to manage finances, however, was said to be difficult for those who were not used to that area. One of our more detailed cases in the interviews involved not only a decision about discharge, but also a matter relating to the patient's will. Both social care and medical personnel said that they did not feel they were the right people to assess capacity in this case, and were relieved when a solicitor said that he felt the patient lacked capacity to change her will. Assessing capacity in relation to finances may thus be both specialised, but often assigned to medical or mental health professionals who would not necessarily have the skills to understand the issues involved. In the telephone survey, we noted that lack of understanding was specifically related in these cases to difficulties in actually calculating money.

Assessment of capacity for financial or property affairs could generally be carried out over a period of time, and indeed, it was found in the online survey that this was so. In particular, the time taken to make a best interests decision was longer for matters relating to property and affairs, and they were more likely to be delayed than other types of decision, so that the person could regain capacity or be helped to be involved in the decision. Moreover, assessing capacity to manage a financial decision was often clearly demarcated and seen as distinct from other forms of decision making. We had several cases in which people were deemed able to manage decisions in most areas of their lives, but were not able to manage financial matters.

Process of best interests decision making

From the online survey, it seemed that most respondents involved in property and affairs decisions were in fact social care or health professionals. As regards the process, most of those claimed to be 'joint decision makers'. Moreover, compared with other types of decisions, property and affairs decisions were more likely to be made over the course of several weeks. This picture of a slow, considered process was fleshed out in the telephone survey. Professionals in health and social care, who may have been alerted to the need to make a best interests decision about someone's money, often felt a keen sense of responsibility in this regard. They often had to turn to solicitors or others who may be able to represent the person, and it was in this area that the legal profession was most often involved. Where appointees or corporate deputies were involved, they still worked jointly with social care professionals in particular, so that their client's wider needs could also be taken into account, as part of the best interests process.

Another reason for a slower process related to the background trigger for the best interests decision. We have mentioned above that some social care decisions were fuelled by a mistrust of family members, and this particularly related to financial abuse or mistrust of the intentions of a relative with regard to someone's property. In those cases, as we saw in the telephone survey and interviews, there was sometimes a long period during which professionals might be aware of a potential problem, but would want to oversee and monitor what was happening.

The result of a best interests decision about someone's financial affairs was often that a corporate deputy, or an individual lay deputy, would take over the money management for

the person lacking capacity. However, that sometimes gave rise to further best interests decisions, when the person wanted to spend some money. For those using corporate appointees, the system for deciding on particular expenditures appeared to involve the person in direct, face-to-face encounters with the council appointees unit. Not only were the appointees able then to oversee individual expenditures, but were also enabled to 'keep an eye' on the person's welfare in general. This appeared to be important for at least some people with mental health problems. The numbers of these cases were very small, however, and so it is difficult to generalise. What might be claimed is that best interests decisions relating to property and affairs were often seen as part of a wider picture; social care needs or health related needs could give rise to concerns about money management, and possible problems in managing property for instance could often come to light at the point when someone's health deteriorated rapidly.

10.2 Trends for different groups of people

10.2.1 People with dementia

People with dementia were a key group for whom best interests decisions were made. They accounted for 40% (154) of the cases discussed in the online survey, 43% of the cases discussed in the telephone survey (29/68) and 32% of the cases discussed in the face-to-face interviews (8/25). Of course, some people with dementia also had additional impairments (such as mental health problems).

Types of decisions made and professional background of decision-makers

Decision-making processes about people with dementia frequently involved a mix of issues relating to health and social care and, less often, property and financial affairs. In contrast to other client groups, most of the social care decisions about people with dementia related to a change of accommodation and only a minority related to safeguarding (62% of as opposed to 8%, as evidenced in the online survey). Accordingly, social care practitioners accounted for the largest single group of professionals who led best interests decisions on behalf of people with dementia (21% of online cases).

Assessing capacity

Professionals frequently made a significant time investment to enable the capacity of people with dementia to be determined and for best interests decisions to be made. Specifically, in almost half of the relevant online cases (48%), the capacity assessments were undertaken

over a period of up to several weeks. In addition, the interviews showed that decision-makers usually tried to facilitate the engagement of, and communication by, people with dementia, including recognising the fluctuating nature of their capacity, involving people familiar to them (such as relatives) and ensuring adequate time for decision-making. However, whilst an impairment must be present for the Act's diagnostic test to be met, this was not always the case. Instead, in at least two telephone cases, where the clients were older people with physical conditions, the finding of a lack of capacity appeared to have been made on the basis of age-related frailty and vulnerability. Similarly, although the Act precludes a finding of incapacity being made simply on the basis of a diagnosis, there was some evidence that this assumption persists as the staff in one care home case initially equated a woman's dementia with a lack of capacity. Likewise, there were instances (particularly in care homes) where it was taken for granted that the clients lacked capacity and it did not appear that their capacity had actually been assessed. Although GPs were often called in to assess the capacity of residents with dementia in care homes, this was sometimes a generic, rather than a decision-specific, assessment. Similarly, GPs and other medical staff sometimes used standardised tests to assess capacity, even though these were ordinarily designed to assess cognitive impairment or dementia. Nevertheless, interviewees such as IMCAs or social workers often disputed or challenged a finding of a lack of capacity if they felt the assessment had not been decision-specific.

Where people with dementia were perceived to lack insight (particularly into their care needs), they were often deemed to lack decision-making capacity. In addition, certain personality characteristics (particularly confabulation and cunning) erroneously assumed to be intrinsic to dementia were evident in some interviewees' descriptions of the factors which informed their finding of a lack of capacity. In contrast with other client groups, the decision-making capacity of people with dementia was often wrongly conflated with their executorial capacity, notably their ability to care for themselves. Whether a person with dementia accepted a particular course of action recommended by professionals (frequently admission to a care home) influenced whether an assessment of capacity was initially undertaken and, in turn, if a finding of capacity was made. More specifically, clients were sometimes found to lack capacity when they were deemed to require admission to a care home but refused to be admitted. In addition, disagreements between professionals about a finding of (in)capacity were sometimes resolved by consecutive capacity assessments being undertaken by

different professionals, whereby the assessment undertaken by the current decision-maker (usually finding a lack of capacity) took priority.

Best interests processes

Professionals usually tried to facilitate the involvement of, and communication by, people with dementia in best interests processes, which commonly consisted of one or more meetings attended by the clients themselves (92% of relevant online cases). Although the relatives or friends of people with dementia were consulted in the majority of instances (89% of online cases), it appeared that IMCAs were not always appointed as necessary in the remaining cases. More specifically, IMCAs were only involved in 8% of the relevant cases (a discrepancy of 3%). Where there were safeguarding concerns about the possible harm posed by people with dementia (to themselves or others), this resulted in their views being weighted less heavily in some decision-making processes than those of their informal carers.

Best interests decisions and outcomes

Best interests processes about people with dementia were necessarily prolonged at times to ensure the right decision was made and for alternative care options to be tried. Whilst concerns about the possible risks faced by people with dementia (or the harm they might pose to others) often prompted 'protective' admissions to care homes, such admissions were also initiated when it was simply a higher level of support that was needed, particularly if this involved 24-hour care. Although difficulties arose with arranging or maintaining domiciliary care when people with dementia did not accept homecare services, this also reflected the inflexible and limited nature of traditional services which are usually not designed with the particular needs of people with dementia in mind (see Boyle, 2010). Likewise, although decisions about the best interests of people with dementia were often tied up with concerns about the best interests of their families, particularly in relation to informal care demands, the limited availability of adequate homecare services made it more difficult to balance one set of interests against the other. It was noteworthy that consideration of a 'less restrictive' option rarely featured in cases relating to people with dementia. Although people with dementia were more likely to experience a major life-changing move than other client groups, they were less likely to be given practical opportunities which would inform their decision-making (such as being taken to view a care home). Although temporary admissions were often used to persuade people with dementia to accept care home admission, as these admissions were frequently not monitored (even by the use of care reviews), the clients had little

recourse to effect any subsequent change in their circumstances. Moreover, there was little evidence that DOLS assessments were undertaken when temporary admissions were subsequently made permanent, but the client had not agreed to a permanent admission (having only assented to a temporary admission). Therefore, overall, it appeared that people with dementia were somewhat disadvantaged in capacity assessment and best interests decisions processes when compared with other client groups.

10.2.2 People with learning disabilities

People with learning disabilities constituted the second largest impairment group in the research. Cases about best interests processes for people with learning disabilities amounted to 131 (34%) at the stage of the online survey, 24 (out of 68) in the telephone survey, and 9 (out of 25) in the interviews.

Types of decisions made and professional background of decision-makers

In the online survey, there were some significant differences between cases involving people with learning disabilities, compared with the remaining cases. For instance, respondents reporting these cases were significantly more likely to be part of a multi-disciplinary team than other respondents, and there appeared to be more decisions reported for them by professionals allied to medicine (PAMS), including for instance occupational therapists or community nurses. These decisions however followed the general pattern reported in the online survey, where health care decisions in general dominated; however, there was a tendency for 'physical health care' decisions to be reported more often for people with learning disabilities than for other groups.

Of the health treatment decisions explored in the telephone survey, 10 were carried out in relation to people with learning disabilities. It seemed that it was often a deterioration in health or a sudden need for treatment, which triggered the need to consider capacity, and often revealed a raft of other issues. For instance, two people with learning disabilities were having problems in eating and were recommended for PEG tube operations, and a man with learning disabilities had to go into hospital for a hip replacement operation, which resulted in his main carer no longer being able to cope. Typically, the availability of support was of vital importance for people with learning disabilities, and so decisions needed to be made not only about their best interests in relation to health treatments, but also in relation to their ongoing support to manage their health.

Assessing capacity

Compared with other groups in the online survey, the assessment of capacity for people with learning disabilities appeared to take place over a longer period of time and they less frequently had an assessment of capacity made on the same day as the best interests decision. In the telephone survey, it became apparent that at least some people with profound learning disabilities were more prone to have a 'standing' assessment of *incapacity*; they were described for instance as 'well known' to services, and in more than one care home, the manager was concerned to ensure that capacity assessments were done in advance by a care manager, so that best interests decisions could be made as needed. This all of course pulls against the spirit of the MCA, in which an assessment of capacity should be both time and decision specific. However, the dilemma of assessing capacity for people with profound learning disabilities did not appear to loom large; since they could not speak for themselves, nor understand what was said to them about a particular matter, their lack of capacity was often spoken of as a matter of common sense.

Where there was no such assumption, however, the capacity assessment for people with learning disabilities tended to be based on a combination of factors; it was often about the lack of communication ability, coupled with an inability to follow the implications of a particular medical treatment or financial calculation, for example. There were some very strong examples in our data of capacity tests being devised, and tools used, which were specific to the decision in question. The telephone survey revealed some very sensitive and differentiated processes, in relation to people with learning disability. For instance, interviewees often spoke about the need to define what type of decision the person could manage, and what type they could not. T15 was the case about moving out of a secure ward, into a community setting. The man with learning disabilities in that case was assessed as being able in general to make that decision for himself, in relation to his own independent living. However, he was not able to understand the nature of his own financial commitments and the necessity to budget for bills. Therefore, a best interests decision was made simply in regard to his finances.

The picture building up about assumptions of incapacity was reinforced in some of the nine cases in the interviews which concerned people with learning disability, who could not express a view for themselves. However, there was a wide range of practice here, and the interview cases included some very strong examples of decision-specific assessments,

about understanding risky behaviour and about financial capability. Participants were also aware of the need to assess capacity at the best time for a particular person, and also to observe their non-verbal cues as well as their verbal behaviour.

Best interests processes

In the online survey, there was also a statistically significant difference between people with learning disabilities and others, in the way that the best interests process was conducted. They more often had decisions made for them in meetings that did not involve them, although they were slightly more likely than other groups to have someone close to them consulted about their best interests. Finally, it also seemed from the online survey that they were less likely than other groups to have best interests decisions that were based on 'all the information available from the best interests process'.

From the telephone survey, it was apparent that people with learning disabilities always had other significant people involved in their lives. That included parents and other family members, residential or home care staff, physiotherapists, day centre staff and many others. Not only were these people consulted about the person's best interests, but they often had to be recruited to the cause, in order to support the person lacking capacity to put into action any decision. An example, for instance, was T38 in which the concern was about a man's mobility needs. The best interests decision was that he should only be lifted into a standing position by using a hoist. However, in order to implement that decision, his mother needed to be persuaded to abide by it, as well as his home staff and his day care staff.

People with learning disabilities were nearly all said to be involved in the best interests process as far as they possibly could be; therefore their lack of involvement in a meeting may be seen in the context of other, more productive ways of finding out their views and preferences. We heard about many person-centred practices with people with learning disabilities in the telephone survey, including the use of Makaton symbols and pictorial systems to assist with communication, and information that included for instance dolls and pictures to try and explain to people about how their body worked. Further, three of the people with learning disabilities in the telephone survey had person-centred plans which allowed others to know in some detail their preferences and needs, and another three had the outcome of the best interests decision recorded for them in an accessible way.

A few cases concerning people with learning disabilities mentioned in the telephone survey were about risks people posed to themselves. Best interests processes in those cases were very much about protecting people, and ensuring that they had the support they needed to keep safe. One of those cases was explored further in the interview stage, and raised a number of very interesting issues. Team work and good communication between professionals were vital in that case, and the best interests decision was only raised at the point when nothing else seemed to work. In other words, every attempt was made to ensure that the man with learning disabilities would protect himself from the risks he was taking, in going out at night and meeting with friends who were exploiting him.

At the interview stage, the nine cases involving people with learning disabilities were equally divided between health, social care and change of accommodation. In the three cases about serious health treatments, although the person themselves was primarily represented by others who knew him or her well, nevertheless participants spoke about how important it was not to over *medicalise* the issues a person might have. The written description of one man, for instance, implied that his health condition was extremely poor. However, when the specialist nurse met him, she realised that he had a strong personality that implied he could express his own view and enjoy his life.

As explored in Section 5 of this report, major best interests decisions were often broken down into sub-decisions. We noted several cases in which the major decision had already been taken, at the point when the person lacking capacity became involved. However, a series of sub-decisions were then explored, and this was the stage when people became more involved. In the interviews, this seemed to be a common pattern with people with learning disabilities. For instance, people who were moving accommodation did not often have a say in whether or not they should move; however, participants explained how they had been involved as much as possible in choosing the place they would go to, selecting furniture or decorates, and so on.

Best interests decisions and outcomes

In summary, then, some trends and patterns in best interests for people with learning disabilities did emerge. People with learning disabilities were more likely to be assumed to lack capacity, and there was certainly an element of 'unwise decision making' in those assumptions for some people who had to be dissuaded from risky behaviours. The MCA was

raised for this group either at the point that their health deteriorated and treatments had to be considered, or in relation to their social care plans. There was a strong element of protection involved in the best interests processes, and other people close to the individual had a relatively strong voice in these processes. We have noted many good practice points as well, in relation to accessible information and informed decision making.

However, one final reflective point needs to be raised. 'Learning disability' is a very broad category, and includes those with profound needs, who will need support to manage every aspect of life. At the other end of the scale, it includes those with 'moderate learning disabilities', who can decide certain things for themselves, and manage aspects of their life. By definition, some people who have a 'mild' learning disability will not be eligible for support services, and it would be very interesting to know if any of those were afforded the same degree of protection as those in our study. It is noteworthy that none of our participants in generic health services mentioned cases where a patient had been found to have a learning disability after admission. The learning disability always seemed to come first, followed by the issue of treatment or personal welfare. Once outside the network of specialist services, the same type of risky behaviour, lack of understanding or lack of insight may well not result in the application of the MCA. Indeed, if the first stage of the capacity assessment is to identify an impairment, there will be cases in which this group will be at risk, since they may not count as disabled. Conversely, one of the perhaps unintended outcomes of the MCA may be that people with learning disabilities who are 'service users' receive an even greater degree of specialist, different treatment than before the Act.

10.2.3 People with mental health problems

Those who had a mental health problem constituted the third largest group in the research, with 107 (28%) in the online survey, 11 (out of 68) in the telephone survey, and 5 (out of 25) in the interviews. As with people with learning disabilities, PAMS staff were more likely than medical practitioners to be involved in their best interests decisions, although they also had a degree of involvement with the ambulance service, with 14 cases relating to people with mental health problems being reported by ambulance staff. A significant finding in the survey relating to types of decision was that people with mental health problems were significantly more likely than others to have *mental health* decisions made for them, rather than physical health care decisions. Their best interests appeared to be considered typically in relation to their mental health needs.

In terms of assessment of capacity, the online survey revealed that there was a significant difference between people with mental illness and those without mental illness when considering the timing. People with mental illness more frequently had the assessment of capacity made on the same day as the best interests decision, compared with all the other groups. However, the best interests process itself was more likely to take place over the course of several weeks. This implies perhaps an urgency in the presentation of a case, but a slightly longer period of time while it was worked out what would be best for the person. In the telephone survey, respondents frequently expressed concern about the difficulties of assessing capacity in people with mental health problems. They often mentioned the fluctuating nature of capacity, and the effect of mood on the capacity to make a decision. For instance, a man moving out of a psychiatric hospital was said to 'not care' about himself any more, and so it was felt by our interviewee that this man was *not* able at that point to make a decision about his own future accommodation. Fluctuating capacity was also discussed in the interviews, in relation to people with mental health problems. Compared with people with dementia or people with learning disabilities, they were more likely to be able to speak for themselves, although conversely, we also had cases described where a person with mental health problems had refused to speak at all. Nevertheless some of our participants worried therefore that the patient or client would come over as capable, when in fact they needed someone else to decide an issue in their best interests. Most worryingly, that scenario was said to apply in life-and-death situations, where perhaps someone either wanted to take their life, or to seek resuscitation at the end of their life.

In the telephone survey, several interviewees explained that a mental health problem would have to be first diagnosed by a psychiatrist, particularly where the person was unknown to services. They then described an assessment of capacity based on irrationality, and a demonstration by the person in question that they were delusional or unreal in their assessment of their options. Again, as with other groups, lack of insight into one's own care needs was frequently mentioned as evidence of lack of capacity. Further, 7 of the decisions in the telephone survey relating to people with mental health problems were about risks and protection. Several of the people who lacked capacity had also been subject to the Mental Health Act, prior to being considered under the MCA. This caused some confusion for our respondents, who often felt that the MCA gave people stronger autonomy and choice. There was at least one case in the study involving a DOLS application, where the MHA might have been more appropriate to use.

The descriptions of best interests processes for people with mental health problems varied widely. For instance, in some cases, it was felt that a large number of people being present would not be appropriate, and in fact escalated the problems encountered. An ambulance man in one of the telephone interviews (T20) was called to a woman who was becoming violent, in a residential care home, and he resolved the situation by persuading her to talk to him in the ambulance, away from other people she knew.

By contrast, other people with mental health problems described in the interviews had a large number of people involved in their best interests process. That could happen in an informal way, as it did in a case about personal care for an inpatient who had come into hospital unkempt and unwashed, and refused to take off his clothes. In his case, the decision making process was very informal, and the consultant and others simply agreed around his bed what was the best way forward. Another case followed up at in the interviews involved a young woman whose financial affairs were managed by corporate appointees, and the best interests decision involved her taking out money for a trip abroad. A social worker, an IMCA and the appointees were involved in this case, as well as the young woman herself. In fact the appointees described how their management of finances for clients with mental health needs often resulted in them being the first to be alerted to social and personal welfare issues, which clients were experiencing.

Of course, mental health problems are not just experienced by a discrete group of individuals. Many people with other impairments or issues had an additional mental health problem, which was interwoven with their best interests decision. These cases tended to be complex, and participants in the interviews spoke about the pains they had gone to, to ensure that clients' mental health needs were attended to. In some cases, however, the mental health problem was mentioned as a factor in determining the outcome of the best interests decision. An example of that was the young woman in F10, whose mental health was said to deteriorate when she had lengthy visits home to see her parents; in a slightly different vein, the man in F09 who needed protection from risky friendships was diagnosed with an additional 'personality disorder', which was said to justify his need for a higher level of residential care and support.

In summary, best interests processes for people with mental health problems were quite diverse. They were characterised by capacity assessments that had to take account of the

fluctuations of mood and illness experienced by this group, and those who assessed capacity often had to rely on issues to do with insight, delusions or confusion. The cases were varied, but many did revolve around the risks people posed to themselves; in some cases, these had to be resolved urgently, but in other cases, a longer process could be undertaken, where someone needed a change of accommodation or a major decision made about their life.

10.2.4 People with neuro-disability

Although there were 75 (19.5%) cases in the online survey concerning someone with a neuro-disability, unfortunately very few of these respondents continued through to further stages of the research. There was only one case in the telephone survey, and two in the interviews, relating to this group. Further, there were no significant differences noted in the online survey in relation to statistics involving people with neuro-disability, and so the few comments made here must be treated as very speculative.

Neuro-disability was used in the online survey to cover both brain injury and neurological illnesses. However, these two types of impairment quite probably present in very different ways, in relation to best interests processes. That point was made at the stage of our focus groups, and was re-iterated in our pilot interviews, both of which concerned people with neurological conditions. One was a person with a brain injury, and it was evident in that case how important the person's past life was, which included his position within his family. A brain injury strikes suddenly, and so this man had undergone a complete change in his lifestyle and capacity overnight. Others involved in his life continued to find that hard to accept, even after several years.

Where people have a neurological illness, more careful preparation could take place. However, assessment of capacity was still an issue, since a patient might be steadily declining. Participants at the focus group stage pointed out how hard it was to pin-point when a patient had lost capacity to make a decision for themselves. They all also said how important it was to include relatives in any best interests decision, and to ensure that information was clearly presented to all parties about the decision to be made. Quite often, these were health-related treatments, such as PEG tube insertion, and the possible benefits and outcomes had to be clearly communicated both to the patient, but also to those close to

them. It would certainly be of great value to follow up this area of best interests practice, particularly with the views and perspectives of family carers in mind.

11. Conclusions and implications

11.1 Contexts for best interests decisions

The best interests principle is only one part of the Mental Capacity Act; yet it does perhaps represent the most innovative aspect of the Act. The argument of 'best interests' as a common law principle permeated legal practice prior to the MCA (Shah, 2010), but it is only since 2007 that the law has laid down the precise conditions and processes which must be in place in England and Wales, where a best interests decision should be made.

This research has revealed that the best interests principle is mainly applied in certain quite well defined situations at present, representing perhaps the 'tip of the iceberg' of places in which the Act could be applied. We should acknowledge first that some of the bias in the data could be due to sampling error in the research; for instance, our evidence about MCA practice in property and affairs decisions is much thinner than in other areas. In general, however, it seemed that the MCA was considered in situations in which people with known impairments were considered to be at risk, either because of their lack of ability to manage life, or because of the risk which they posed to themselves (see also Boyle, 2011). Often, the business of 'risk assessment' was a complex one, but in our data it was particularly associated with people who were refusing elements of their care or support, or with people whose ability to manage everyday life was affected by an impairment such as dementia. The MCA gave professionals a legal basis for intervening in such situations, and acting to protect the person who lacks capacity. Moreover, we found also that these risks often became apparent when people's health deteriorated, and that the need for serious health care interventions could precipitate a more considered look at other aspects of a person's life. Therefore, much of the practice we were able to investigate stemmed from health care, but extended into social care or financial decisions.

Gaps which were noticed in application of the best interests principle related firstly to everyday, routine decisions (see also Manthorpe et al., 2011), and secondly to care planning and personal budgets. The latter gap was also found in Williams and Porter (2011) in research about support planning for the Office for Disability Issues, and is currently the topic of a new research study funded by the SSCR. Both aspects of practice would be very important to many people who lack capacity, since their best interests would need to be

determined according to the principles of the Act, at the point when they are assessed for social care services, when decisions are made about their personal budget or care plan, and when they are actually receiving care and support.

Most typical of all the practices described in this report was the situation where a decision needed to be made about discharge from hospital, or when a change of accommodation was on the table. At that point, the wish of someone to return home had to be weighed up against their safety. These major life decisions were salient enough for practitioners to realise that their actions should be guided by the legal framework of the MCA.

We noticed, however, that there were very few reports of the MCA being used for people who did not already have recognised impairments. The vast majority of those for whom best interests decisions were made already used social care services, were in hospital, were resident in care homes, or had some form of support which singled them out as 'service users'. It seemed then that the MCA was being applied less in making best interests decisions for people without an impairment, but who had become temporarily incapacitated. Similarly, it seemed that people were identified as needing a best interests process *because of* a known impairment as well as lacking capacity to make a decision; there were virtually no cases described where a person who was not already known to specialist services had their capacity questioned in relation to a specific decision.

11.2 Assessment of capacity

The most common area of concern amongst practitioners in this research related to assessment of capacity. This accords with other recent research (Willner *et al.*, 2010; Oldreive and Waight, 2011), which has highlighted shortcomings in assessing capacity amongst both social care and health professionals. In the current research, the distinction between being supported to make a decision and lacking capacity was often blurred, fluctuating and difficult to determine. Further, there was a dilemma about the difference between someone with capacity who made an 'unwise decision' and someone who lacked capacity, as also found by Willner *et al.* (2010). The two matters were often confusingly conflated within the notion of 'lack of insight' which was a commonly cited reason for assessing a lack of capacity. Throughout this report, people were described who effectively lacked awareness of the level of their own support needs, and that lack of awareness was equated with a lack of capacity. There was some evidence that people with dementia, and older people in general, were relatively disadvantaged in respect to capacity assessment.

There were occasions on which general cognitive tests were used to assess capacity, rather than decision specific processes. There were also occasions on which a lack of capacity was presumed, simply on the basis of age and frailty, thus essentially flouting the two-stage capacity test, in which an impairment has to be present.

Other research (Skinner, 2011) has also recently suggested that capacity assessments may not always follow a rigorous process, and clinicians in particular (Roy et al., 2011) have been singled out as not regularly recording assessments of capacity. Lepping (2011) further revealed that senior medical and psychiatric staff frequently overestimated their patients' mental capacity, and Lepping was consequently critical of health care practice in relation to the MCA. The current research has largely explored 'best practice' and has been able to report on the turning tide of practice in health care adherence to the MCA. Therefore, the lack of rigor and recording of capacity assessments could be addressed by some of the practices explored in this report, including the multi-disciplinary modes of capacity assessment, the informal conversations that were carried out and which fed into a total picture of capacity and the way in which clinicians and others were prepared to consult, and to go back several times, to assess a patient whose capacity might have fluctuated. However, even the relatively well-informed practitioners in the current research had concerns about the difficulty of assessing capacity. Because they were amongst the more sensitive and experienced in using the MCA, they were also most able to pinpoint the dilemmas inherent in the Act. For instance, this research has indicated how capacity assessments could be unduly influenced either by someone's strong and vocal personality, or conversely by their lack of ability to speak up. Further, it was quite clear from many of our examples that the theoretical logic of the Act, where best interests decisions neatly follow on from capacity assessments, did not generally match real life situations. In fact, it was more common to find that best interests decisions and capacity assessments were interrelated, and we have called that the 'concertina effect' in this report.

11.3 Best interests processes

Consistently, this research has shown how reluctant practitioners were in describing themselves as a 'sole' decision maker. There was a preference for joint, consensus decision making expressed at every stage, from the online survey through to the interviews. This finding concurs with other recent research; Willner et al (2011) found that community learning disability teams assuming responsibility for decision making would belong to a team

rather than a 'decision maker'. In the focus group stage of the current research, it was felt that social care practitioners in particular would naturally prefer multi-disciplinary, consensus approaches to best interests decisions. However, the research has revealed that this is also true of much practice in health care. Multi-disciplinary models of decision making were particularly successful when they allowed teams to re-visit cases on a regular basis, and to ensure that best interests decisions were not missed for their clients or patients.

Meetings were by no means the only model of best interests decision making in this research, although the preference for meetings was clearly linked with the desire for consensus. There were occasional hints that the reluctance to take sole responsibility for a best interests decision could result in delays, which could in some cases prove fatal.

However, Section 4 of this report explores some different models, in which good preparation and information gathering led to successful meetings, where a best interests decision could be discussed. As shown in the detailed case studies in Appendix C, the function of meetings was not always to actually *make* a decision, but rather to convey that decision to all concerned. The gravitas of a meeting ensured sometimes that the person lacking capacity knew what had been decided, and had an opportunity to discuss the implications.

An important finding from this research related to the area of conflict and disagreement.

Disagreements were a natural part of best interests decisions, but several of our respondents felt uneasy about this type of conflict. IMCAs were more often instructed in cases where conflict existed, but unlike Townsley & Laing (2011) who examined outcomes of decisions from the point of view of IMCAs themselves, this research showed how an IMCA could sometimes be seen as exacerbating the problem. Moreover, time delays in receiving IMCA reports meant that in some cases, IMCA involvement did not support the process very efficiently. IMCAs were seen as being most successful in situations where there were no particular time constraints, and where they could provide a full, rounded picture of the person's needs, background and wants.

Perhaps one of the most useful aspects of the current research was the outline of different models and processes in making best interests decisions. It was shown, for instance, how important it was to have flexible processes, which were tailored to the particular situation, and in which informal meetings and information were well recorded, so that they could 'feed in' to more formal meetings. Further, good preparation and leadership in best interests meetings were both vital in assuring a successful outcome. Where information was not well recorded, or shared, unnecessary delays could occur and professional antagonism and

confusion sometimes obscured the best interests of the client. Therefore, we could see how important it was to find ways to be efficient and timely in recording and sharing information, and in planning out a process that really did include the relevant people and the relevant information. At times, good best interests leaders also instigated actions between meetings, and spent time in ensuring that they were carried out effectively.

11.4 Outcomes of a best interests decision

We have emphasised in this report that the best interests principle should not just be about decisions, but also about action. That point arose from the focus groups, and was followed through in discussion with participants about the outcome of the best interests decision. It was found, for instance, that the most common outcome for people lacking capacity was a move towards a more protected living environment, or a greater level of restrictions to protect them from risks. In other words, in common with Boyle (2008) and Collopy (1995), we often found that the capacity to make a decision became interwoven with the capacity to manage one's life.

We also found that a good process of best interests decision-making did not necessarily lead to a good outcome. That was often because of frustrations related to availability of provision, resources or services. Therefore, it would seem that the MCA, although representing a legal framework, is often trumped by what is possible and available through the public purse. Further, there were situations in which outcomes could only be achieved by the compliance of everyone concerned with the person lacking capacity. In successful cases, those making the best interests decision had been aware of the importance of staff training, ongoing support and input. Those factors also applied to family members, who had sometimes to effectively implement a best interests decision.

All those factors could mean that a best interests decision took a long time, both to make, but also to implement. That delay was sometimes actually a useful factor in the process, from the point of view of the person lacking capacity. Sometimes it allowed more options to be explored, and at other times it allowed the person to regain capacity or understand some of the issues they faced. However, delay was not always in a person's best interests, and there were cases in which delays could prove fatal. Therefore, the timescale for action in a best interests process needed to be sensitive to the particular circumstances of the case. The decisions in this research ranged from urgent to very lengthy, considered approaches.

11.5 Confusions

Despite the relatively experienced and confident sample of practitioners in this research, there were some indications that practices were at times insufficient. There appeared to be a general lack of awareness of the use of DOLS in many of the cases (see also Gantley, 2009, in Boyle, 2011), and we are aware that further research (Langan et al) is ongoing on that issue. However, from the current study, we can hypothesize that there is a 'grey area' where a decision has to be made about protection and safeguarding. In those cases, it seemed as though there was often an assumption that the person lacking capacity needed some type of restriction, and in several of those cases the person themselves was refusing or resisting that restriction. Temporary admissions to care were sometimes used in an excessively restrictive way, and were routes to professionals enforcing a decision for someone who initially was not compliant. Therefore, DOLs applications seem to be under-used, perhaps particularly by those professionals involved in safeguarding processes.

Confusions emerged in other areas as well. Participants in interviews often confused the Mental Health Act (MHA) with the Mental Capacity Act, and that was particularly so in mental health services. The MHA was perceived as clearer, and easier to enforce. This confusion possibly manifested itself also in the difficulty of assessing capacity in people with mental health problems.

There were additional confusions about some aspects of the MCA itself, in particular perhaps relating to capacity assessment and to roles. Firstly, there were cases in this research where a best interests process appeared to have been undertaken, without any assessment of capacity. There was clearly confusion amongst a minority of participants about the fundamental link between capacity and best interests. Further, we have already mentioned the difficulty for people of taking up the role of decision maker, but there was often also confusion in their understanding of the IMCA role, as also indicated by Redley *et al.* (2008) and Manthorpe and Martineau (2010). For instance, we found, as did Townsley and Laing (2011), that IMCAs tended to be instructed in situations where no-one else was available to advise professionals on how to proceed. They were then given higher status than the MCA allows, in that they were expected on occasions to actually take the decision, to advise others, and to resolve conflicts with families. Arguably, the extension of the IMCA role was very useful in some cases, particularly where the decision was about suspected abuse within families. However, there is probably room for greater clarity and dissemination of the

fundamental purpose of IMCAs. The continued knowledge gaps in relation to the MCA could perhaps be filled better by secure funding for local experts on the MCA, and by improved guidance and support at all levels of the health and social care workforce.

11.6 Dilemmas

In social care practice in particular, the dilemma faced by staff was the tension between supporting autonomy and protecting their clients by making decisions for them. In health care, by contrast, the dilemma was more often seen as reconciling the need to heal a patient's physical condition with the need to consider their capacity and wider, holistic concerns about their life. We noted also a general concern about the notion of best interests itself, since it inevitably foregrounds the rights of one individual, sometimes over the rights of others. For instance, there was a particular dilemma for participants when a family carer's rights and needs had to be considered alongside those of the person lacking capacity. Arguably, it was not always in the best interests of the individual person to ignore the needs of those around them. Several of our participants spoke about striking the right balance. This balancing act was also connected, naturally, with the desire to avoid or solve conflicts. However, this research has argued that conflicts *per se* are not necessarily indicative of bad practice; on the contrary, tackling a conflict more openly may actually be in the best interests of the person lacking capacity, in certain circumstances. For instance, in situations where family members or friends were suspected of abuse or financial misdemeanours, the MCA allowed participants to act on behalf of the person lacking capacity. It was hard, though, for professionals to know when to accept and tackle conflicts between people, and when to reconcile and seek a balanced approach.

Finally, the best interests principle raised a dilemma about the philosophical question of what a decision actually is. The ability to make a decision is closely linked with human autonomy, and as such might appear to be an individual trait of human beings. However, in general social life, decision making is often a joint activity; it is also undertaken in care home situations through interaction between staff and clients (Jepson, 2011; Williams, 2011). As we have emphasised in this research, there was also a strong preference expressed by participants to carry out *joint* work, and perhaps that is only to be expected, given their experience of how they themselves would seek a decision about their own lives. It would seem to be in order to carry out more discussion about these matters with those who have

some experience now of using the MCA; participants in the current research were often very keen to discuss aspects of the MCA, and to reflect on the meaning inherent in their practice.

11.7 Solutions in practice

Research about the implementation of the MCA has largely to date revealed insufficiencies and gaps. While that element has also been noted in the current research, nevertheless we were fortunate in being able to survey practice amongst reasonably experienced and confident practitioners, in health, social care and in property and legal affairs. Therefore, we trust that this research can contribute to improving practice simply by disseminating some of the solutions and good practice identified. For instance, through analysis of some of the cases in the telephone survey and interviews, we were able to identify several elements of strong leadership which could be useful in providing education and training for practitioners. Linked with the points made above about best interests processes and models, this research also emphasized the value of providing good information, recording best interests processes efficiently, and being open and timely in sharing information and planned actions. In all this, practitioners valued highly a local source of support, most often citing a colleague, a named MCA lead in their Trust, or a local MCA advisor as having provided invaluable advice. Practitioners said that they needed that advice when faced with the complexity of a real case, rather than just having training about implementing the best interests principle 'in theory only'. In particular, people spoke about the value of linking this type of support and advice to their own particular professional role.

A final but important point related to the way in which people lacking capacity were supported, on occasions, to take part in decisions, to express a view, or to show how they might feel about a particular course of action. Accessible information was developed in several cases, both to record and explain the process of the decision, but also to describe more effectively the parameters of the decision that had to be made. People were also involved in decision making by going to see the alternative places which they had to choose from, or by having real and concrete experiences that could help them to understand what professionals were talking about. All these aspects of good practice could be more widely disseminated; nevertheless they were important findings of the current research and could help to keep the person lacking capacity at the centre of decisions in their life.

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Glossary

Assessment of capacity

The law says someone lacking capacity cannot do one or more of the following four things:

- Understand information given to them
- Retain that information long enough to be able to make a decision
- Weigh up the information available to make a decision
- Communicate their decision.

Best Interests decision

- The Mental Capacity Act (MCA) states that if a person lacks mental capacity to make a particular decision then whoever is making that decision or taking any action on that person's behalf must do this in the person's **best interests**. This is one of the **principles of the MCA**.

Code of Practice

The Code of Practice supports the MCA and provides guidance to all those who care for and/or make decisions on behalf of adults who lack capacity. Professionals working under the Mental Capacity Act must have regard to the Code of Practice.

Decision Maker

The person who has to make a Best Interests decision for a person lacking capacity, is known as the 'decision-maker' and normally will be the carer responsible for the day to day care (including both care staff, relatives or friends), or a professional such as a doctor, nurse or social worker where decisions about treatment, care arrangements or accommodation have to be made. The Code of Practice commonly refers to a 'decision maker' as one person, but there is an acknowledgment that in some cases a joint decision might be made by a number of people.

Deprivation of Liberty Safeguards (DOLS)

The Deprivation of Liberty Safeguards (DOLS) were introduced into the Mental Capacity Act (2005) through the Mental Health Act (2007). The legislation provides a legal framework for authorising a deprivation of liberty so that treatment or care can be provided in a care home or hospital (the Managing Authority) for people who lack mental capacity.

Deputy

Deputies are appointed by the Court of Protection to manage the property and affairs and/or personal welfare of someone who lacks capacity to make certain decisions for themselves. If a person has not appointed an attorney, or if they do not have the mental capacity to make a power of attorney, there might be the need for the Court to appoint a deputy.

Independent Mental Capacity Advocate (IMCA)

An IMCA is a type of official advocacy role introduced and required by the Mental Capacity Act 2005. The Act gives some people who lack capacity the right to receive support from an IMCA. IMCA services are provided by organisations that are independent from the NHS and Local Authorities

Lasting Power of Attorney (LPA)

A Lasting Power of Attorney (LPA) is a legal document. It allows a person to appoint someone as an 'attorney' to make decisions on their behalf if in the future they lack the mental capacity to do so.

Mental Capacity Act (MCA)

The Mental Capacity Act provides a framework to empower and protect people who may lack capacity to make some decisions for themselves. It was implemented in England and Wales in 2007. To have mental capacity means being able to make your own decisions.

Office of the Public Guardian (OPG)

The OPG is the Government Agency with responsibility for mental capacity policy, and provides guidance to public, legal and health professionals.

The principles of the Mental Capacity Act (the 5 principles)

The MCA is underpinned by 5 principles:

- a presumption of capacity - every adult has the right to make his or her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
- the right for individuals to be supported to make their own decisions - people must be given all appropriate help before anyone concludes that they cannot make their own decisions
- that individuals must retain the right to make what might be seen as eccentric or unwise decisions
- best interests - anything done for or on behalf of people without capacity must be in their best interests
- least restrictive intervention - anything done for or on behalf of people without capacity should be an option that is less restrictive of their basic - as long as it is still in their best interests.

Two-stage test / Capacity Test

Under the MCA, capacity to make a specific decision at a specific time, is assessed using a two stage test. Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity, by considering:

- Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.)
- If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

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