Scottish Parliament Region: Mid Scotland and Fife

Case 200502634: Fife NHS Board

Summary of Investigation

Category

Health: Hospital; NHS Funded Continuing Care

Overview

The complainants, a firm of solicitors (the Solicitors) raised a concern on behalf of their clients, the family of Mr A, that Mr A had not been properly assessed by Fife NHS Board (the Board) and consequently was not receiving funding for NHS Continuing Care. The family were also concerned that they had not been able to appeal against the decision not to fund Mr A's care.

Specific complaints and conclusions

The complaints which have been investigated are that the Board failed to:

(a) properly assess Mr A for his continuing health needs and to provide details of the criteria used in deciding to discharge Mr A from in-patient care (*not upheld*); and

(b) consider an appeal against the decision to refuse funding (*upheld*).

Redress and recommendations

The Ombudsman recommends that the Board:

(i) make a formal, evidenced record of decisions to discharge and that this record is provided to the patient and/or family in a timely manner; and

(ii) ensure that when a decision to discharge is reached such a decision is made known to the patient and/or family at the time the decision is taken and that where objections are presented the process for appealing against such a decision is clearly and fully explained.

Further Action

This and other complaints to the Ombudsman indicate an urgent need to review the guidance on NHS Funded Continuing Care which was issued more than 11 years ago. This is not a matter which an individual Health Board is able to address so cannot be resolved within this report. The Ombudsman will instead draw this matter to the attention of the Scottish Executive Health Department.

The Board have accepted the recommendations and will act on them accordingly

Main Investigation Report

Introduction

1. On 21 December 2005, the Ombudsman received a complaint from a firm of solicitors (the Solicitors) on behalf of the family (the Family) of Mr A about the assessment of the eligibility of Mr A for NHS funded Continuing Care by Fife NHS Board (the Board). The main events referred to in this report occurred between June 2005 and October 2005. The Family first raised the general matter with the Board, through the Solicitors, on 29 August 2005 and formally sought to appeal the decision to discharge on 7 October 2005. An appeal was denied by the Board because more than one month had elapsed since the Family were informed about the appeal process to challenge the original decision to discharge. The Family then made a complaint to the Board. A response to the complaint was sent on 24 November 2005 but the Family remained unhappy and asked this office to investigate the matter.

2. The complaints from the Family which I have investigated are that the Board failed to:

(a) properly assess Mr A for his continuing health needs and to provide details of the criteria used in deciding to discharge Mr A from in-patient care; and

(b) consider an appeal against the decision to refuse funding.

3. As the investigation progressed, I identified issues concerning the clarity, accessibility and transparency of the process for assessing eligibility for NHS funded Continuing Care. These issues have also been identified in other investigations conducted by the Ombudsman's office. The Ombudsman will, therefore, be forwarding a copy of this report to the Scottish Executive Health Department (SEHD) to consider its implications for two reviews currently being undertaken by SEHD (see paragraphs 32 to 34).

Background Legislation, Case Law and Guidance

Scottish Guidance, Legislation and Case Law

4. The National Health Service (Scotland) Act 1978 (the 78 Act), section 1, outlines the general duty of the Secretary of State (now the Scottish Ministers) to promote a comprehensive and integrated health service and to provide or secure the effective provision of services for that purpose. Section 36 of the 78 Act relates specifically to the provision of nursing and other services considered necessary to meet all reasonable requirements (see Annex 2). The duty placed on local authorities in Scotland by the Social Work (Scotland) Act

1968 (the 68 Act) is to promote social welfare by making available advice, guidance and assistance as appropriate (this will include the provision of residential and other establishments). Both the 68 and the 78 Act are relevant to the decisions in this case.

5. Each NHS Board in Scotland has a duty to meet the health care needs of people in its geographical area who require continuing health care. This care is commonly referred to as NHS funded Continuing Care and can be provided in a number of settings but is paid for entirely by NHS Boards.

6. Each NHS Board also has a duty to ensure any necessary arrangements are in place for in-patients prior to discharge. Responsibility for making these arrangements will vary according to the particular needs of each patient. The decision to discharge is made by the doctor responsible for the patient's care and is a clinical decision. In some cases it will also involve joint working between hospital staff, the GP and social services staff (in fulfilment of their obligations under the 68 Act). Where there are costs involved in meeting the particular needs identified these can be met in a number of ways including self-funding by the patient (or the patient's family), local authority funding (which will vary according to need and circumstance) or NHS funded Continuing Care as appropriate.

7. A circular was issued in 1996 by the then Scottish Office Department of Health (MEL 1996 (22) – referred to in this report as the MEL) setting out both the responsibilities of the NHS to arrange discharge and the criteria for NHS funded Continuing Care. Annex A of the MEL states that the NHS should arrange and fund an adequate level of service to meet the needs of people who because of the 'nature, complexity or intensity of their health care needs will require continuing in-patient care … in hospital … or in a nursing home'.

8. The MEL sets out in greater detail a number of criteria which all Health Boards must cover for their locality. Paragraph 16 of the MEL sets out the nature of the assessment of health needs which is to be carried out. Paragraph 20 sets out the eligibility criteria for NHS continuing care. Paragraph 5 of Annex A to the MEL sets out similar general principles. As relevant to Mr A's situation the conditions can be summarised as applying to those circumstances where either a patient needs ongoing and regular specialist clinical supervision on account of the complexity, nature or intensity of his or her health needs; or, a patient requires routine use of specialist health

care equipment or treatments requiring the supervision of NHS staff; or, a patient has a rapidly degenerating or unstable condition which means they will require specialist medical or nursing supervision. At the time the MEL was issued, similar guidance was issued for England and Wales. The situation in England and Wales has developed significantly since 1996 as a result of a number of important judgements by the Court of Appeal and the High Court (see Annex 2) and reports issued by the Health Services Ombudsman for England in January 2003 and December 2004 (see Annex 2). These developments attracted considerable media attention as a result of which the NHS in Scotland received a number of complaints about the funding of Continuing Care. The SEHD Directorate of Service Policy and Planning issued a letter (DKQ/1/44) to all NHS Chief Executives on 13 June 2003, outlining the process for handling such complaints. In summary the current position with regard to guidance issued by SEHD on NHS funded continuing care in Scotland remains limited to that set out by the MEL.

Investigation

9. Investigation of this complaint involved reviewing Mr A's relevant hospital records and the Board complaint file; obtaining the opinion of a clinical adviser to the Ombudsman (referred to in this report as the Adviser); reading the documentation provided by the Solicitors; identifying relevant legislation and reviewing policies and procedures. In July 2006 this office raised a number of the concerns identified in this complaint and a number of other cases being considered by this office with the SEHD and subsequently sought legal advice on certain matters. A summary of terms used is contained in Annex 1. A list and detailed summary of the Scottish legislation, policies and reports considered in this report is in Annex 2. A summary of the problems identified by the Ombudsman's office with the procedure for operating the MEL is contained in Annex 3. I have not included in this report every detail investigated but I am satisfied that no matter of significance has been overlooked.

10. In their complaint to this office the Solicitors raised issues about the relevant SEHD guidelines. These guidelines are the responsibility of the SEHD and cannot be addressed directly within this investigation which concerns the Board. However, this and other complaints currently with the Ombudsman's office raise broader policy issues which the Ombudsman has drawn to the attention of SEHD in a previous report (200500976).

(a) The Board failed to properly assess Mr A for his continuing health needs and to provide details of the criteria used in deciding to discharge Mr A from in-patient care

11. Mr A, then aged 75, was admitted for assessment to the old age psychiatry unit in Whyteman's Brae Hospital (the Hospital) on 19 May 2005 following an acute episode of dementia. Although Mr A was physically well his condition took some time to stabilise and he was detained under section 23 of the Mental Health (Scotland) Act 1984 shortly after his admission. He also required assistance and prompting in personal care. At a meeting which included a number of members of the Family at the Hospital on 27 June 2005 the option of placing Mr A in a nursing home under a guardianship order was discussed. At that time it appeared that all parties agreed to this. The consultant in charge of Mr A's care (Consultant 1) discussed the matter again on 9 August 2005 with Mr A's wife (Mrs A), who expressed a preference for her husband to stay in long-term hospital care rather than be placed in a nursing home. A further meeting was held on 29 August 2005 at which the Family were accompanied by the Solicitors. At this meeting the Family were advised that a Guardianship Order was to be applied for by Fife Council under the Adults with Incapacity (Scotland) Act 2002 as Mr A lacked the capacity to make decisions for himself. His discharge would be arranged thereafter. The Solicitors objected to the decision by the Board not to fund Mr A's continuing care and the application for a Guardianship Order.

12. An appeal against the discharge decision was lodged on 7 October 2005 (see Complaint (b)). On 4 October 2005 the Solicitors had received a letter from the Board advising that the eligibility criteria for NHS funded Continuing Care were outlined in the MEL, but that Mr A did not meet these criteria and would be discharged. Consultant 1 met with Mrs A and family members on 13 October 2005 and 15 December 2005 to try and resolve matters. Mr A's condition deteriorated and his discharge was postponed. Mr A was finally discharged to a nursing home on 1 March 2006.

13. The Adviser told me that the nursing records were detailed and regularly updated and showed that ward staff regularly assessed Mr A. The clinical records indicate that Mr A was given a high standard of care and treatment in the Hospital. The Adviser told me that Mr A's medication required frequent revision due to side-effects and adverse reactions while his mental state fluctuated. The Adviser noted that on his admission to the nursing home Mr A was still confused and having visual hallucinations, he was unsteady on his feet

and required considerable assistance with personal care (eating and drinking in particular). On discharge it was necessary for a Community Psychiatric Nurse to carry out monitoring visits to Mr A. The Adviser concluded that Mr A's care needs were considerable and could be regarded as unpredictable and intense with specialist input, all of which can be regarded as qualifying criteria under the MEL (see paragraph 7 and 8).

14. The Adviser noted that a formal assessment of Mr A under the MEL was not recorded in the medical records, although the records do indicate a number of multi-disciplinary team meetings and discussions with the Family.

15. In response to a draft of this report written comments were received from the Board and I met with relevant staff from the Board, including Consultant 1. Consultant 1 told me that she considered that she did use the criteria set out in the MEL and the Board disagreed with the Adviser's view that the MEL criteria might suggest that Consultant 1's decision was open to question. The Board also noted that Mr A's condition had deteriorated significantly following his discharge and he required to be readmitted but that his condition had been reasonably stable in the three months prior to discharge.

16. The Board also noted that the MEL is not a formal assessment tool and has no formal procedure for assessment. Given that, they did not consider that there was a failure to properly consider eligibility under the MEL. Further, the Board questioned what level of evidence could feasibly be provided beyond the fact that Consultant 1 and the multi-disciplinary team had reached a clinical judgement that Mr A did not meet the criteria for NHS Continuing Care.

17. In discussion with staff it became apparent that they took the view that any patient in Fife who required NHS Continuing Care could only receive such care within a NHS Fife in-patient's area. The view was that, as there had to be a requirement for specialist input and such specialist input was only available in an in-patient setting, anyone who could be cared for elsewhere could not be eligible for NHS Continuing Care. In saying this the Board were not implying NHS Continuing Care could only ever be provided in an in-patient facility. However, for Fife this was the case as no care home in the area could provide the level of specialist input required.

(a) Conclusion

18. In considering any complaint about the NHS the Ombudsman's office has to reach a view on whether the person on whose behalf the complaint is made has been caused injustice or hardship by clinical failings, maladministration or service failure. I have seen no evidence of clinical failings in the Board's dealings with Mr A. Indeed, I note that the Adviser considers Mr A received a high standard of care and treatment in the Hospital.

19. If, in considering Mr A's eligibility for NHS funded Continuing Care, the Board had failed to act in accordance with the MEL that would constitute maladministration which might have caused injustice or hardship to Mr A. The Adviser considers that the view of the Board that Mr A would not have qualified for NHS funded Continuing Care may be open to question. However, that does not necessarily mean that the Board's view is wrong or that there was fault in the process by which it was reached. The Board consider that the view they have reached is fully in accordance with the MEL and I am aware that the position they take, and the processes by which they have arrived at it, are in line with those taken by other NHS Boards in similar circumstances. The MEL did not require any formal assessment or record of why Mr A was not considered to meet the criteria for NHS funded Continuing care and I do not consider the lack of such a formal assessment by the Board to be otherwise maladministrative. The Board advised the Solicitors that the criteria used to guide discharge decisions in this case were those of the MEL. The MEL does not require the Board to put local criteria in place and the Board had no such local criteria. There was, therefore, no maladministration as details of the criteria used were provided.

20. Was there service failure? Section 5(2) of the Scottish Public Services Ombudsman Act 2002 defines service failure as any failure in a service provided by an authority or 'any failure of the authority to provide a service which it was a function of the authority to provide'. If someone has needs which are complex, intense and of a nature that would be beyond what a local authority ought to provide under its duties in terms of the 68 Act, then the relevant Health Board has a responsibility under the 78 Act to provide (in the individual's home or elsewhere) such medical, nursing and other services as they consider necessary to 'meet all reasonable requirements' (see Annex 2). It is not the role of the Ombudsman's office to determine what services are necessary to 'meet all reasonable requirements'. However, if the interpretation and application of the 'specialist' input criterion in the MEL acted as an impediment to the provision of self-evidently 'necessary services' through NHS

funded Continuing Care, it would be reasonable for this office to conclude that there had been service failure. On the evidence available to me in this case I cannot reach such a conclusion and, therefore, cannot conclude that Mr A was not properly assessed. I, therefore, do not uphold this complaint.

21. However, while I do not have prima facie evidence of service failure the reliance on the use of the word 'specialist' in the MEL is a concern. This case and a number of others with this office suggest the MEL may be being interpreted in a way which means patients who have a sufficiently high level of health care need are potentially excluded from NHS Continuing Care because their overall care needs cannot overcome the hurdle of requiring 'specialist' input. This would potentially prevent a Health Board from doing something it ought to do under the 78 Act. If this is the case then the Health Board is obliged to follow its legal duty, which may override the guidance if the guidance fails to reflect the law. The Board consider they are correctly applying the MEL but this case begs the question of whether the MEL properly reflects the legal provenance for NHS funded Continuing Care. This is not a question that this office can determine but does lead me to conclude that unremedied injustice may be caused by the application of the MEL.

22. The concern and belief that this unremedied injustice exists is at the core of all the complaints about Continuing Care brought to this office. This will continue to cause distress and anxiety for patients and their families at a time when they are especially vulnerable and to take up a considerable amount of NHS time and resources in addressing these. This office will, in turn, continue to receive complaints which we are unable to determine. Further to the core concern about the legitimacy of the application of the MEL, Annex 3 sets out a number of other concerns about the operation of the MEL.

(a) Recommendation

23. In light of the conclusion in paragraph 21 the Ombudsman has no recommendation to make to the Board but in light of the conclusions in paragraph 22 and 23 will be referring this report to the SEHD, once again stressing the urgent need for completion of the review of the MEL.

(b) The Board failed to consider an appeal against the decision to refuse funding

24. The Solicitors sought to appeal the decision of the Board in a letter dated 7 October 2005 but were subsequently advised that the appeal period was only ten days. The original decision to discharge was reached in June 2005 but the Family were informed of the right to appeal at the meeting on 29 August 2005. On 2 September 2005 the Solicitors wrote to Consultant 1 asking for details of the reasons for Mr A's discharge and a medical report. They received a negative response to this on 12 September 2005 and challenged this on 15 September 2005 and again on the 22, 27 and 28 September receiving a response on 4 October 2005. The appeal itself was not made until 7 October 2005, following the further exchange of letters between the Board and the Solicitors. The Board considered that this significantly exceeded the time limit of ten days allowed by the appeal process for lodging an appeal and thus that the period had expired. The Solicitors objected to this stating that the Family were not advised of any right of appeal or the timescale involved at the time of the decision to discharge first being taken. The Board responded that it was not the usual practice to advise of the right of appeal unless a family clearly disagreed with the discharge decision and that this was not the case for Mr A's family at the time the discharge decision was reached. Once this became apparent at the August meeting, the family were informed of the right of appeal with the ten days being deemed to run only from this point (29 August 2005).

25. From my discussions with the Board it does not appear that the family were told of the ten day time limit during the meeting on 29 August 2005. The Board felt, however, that the Solicitors, who were present at that meeting, were aware of the time limit.

26. Advice to health boards regarding the process for review of decisions to discharge and regarding NHS funding of Continuing Care is set out in a letter issued by SEHD Directorate of Service Policy and Planning (DKQ/1/44) to all NHS Chief Executives on 13 June 2003. The letter states that where a patient is still receiving in-patient care the decision should be reviewed in accordance with the guidance in the MEL. If a patient has been discharged the decision should be reviewed in accordance with the NHS Complaints Procedure. In Mr A's case, the appeal against discharge fell to be processed under the MEL guidance and the Board correctly stated that such an appeal required to be lodged within ten days.

27. In response to my enquiries the Board advised me that it is not the current practice in mental health services to maintain or issue a separate recording of meetings to discuss and plan discharge although notes are made in the patient's records. The Board acknowledged that providing a summary of the discussion and clinical judgement about discharge and any decisions agreed would represent good practice and allow time for reflection for those concerned. The Board provided me with sight of the Board Joint Hospital Discharge Protocol (dated 20 December 2005) which contains a suggested template for this purpose but noted that this may not be being widely used across all services. The Board also provided me with a copy of the appeals process which is handed out where there is a dispute over the discharge arrangements. I have reviewed both the documents provided and consider their use in Mr A's case would have been of considerable benefit in resolving a number of issues in this complaint.

(b) Conclusion

28. It is very unlikely that a family will be familiar with the process for hospital discharge and/or continuing care assessment and consequently I do not consider it is reasonable to expect relatives to take on board all that is being said to them by medical professionals and instantly consider all the implications of decisions reached at a meeting. It is important that any appeal process is well known and transparent. By not giving full information about the appeal mechanism and subsequently denying an appeal on grounds of time the Board effectively denied the Family access to due process. I consider that the Board acted reasonably in making the information about the appeal process known at the meeting on 29 August 2005 but did not make the timescale for this known. The Board subsequently denied a request for a formal appeal because it was time-barred. While I appreciate that it was reasonable to assume that the Solicitors would be aware of the timescale for appeal I do not consider that the Board could delegate its duty to inform the Family of the timescale and that consequently denying an appeal was unreasonable. I, therefore, uphold the complaint that the Board failed to consider an appeal against the decision to refuse funding.

(b) Recommendation

29. The Ombudsman notes that the Board's existing documentation on appeals and discharge (referred to in paragraph 27) would have resolved the difficulties in this heading of complaint. The Ombudsman recommends that the

Board make a formal, evidenced record of decisions to discharge and that this record is provided to the patient and/or family in a timely manner.

30. The Ombudsman further recommends that the Board ensure that when a decision to discharge is reached, such a decision is clearly made known to the patient and/or family at the time the decision is taken and where objections are presented the process for appealing against such a decision is clearly and fully explained.

Wider Policy Issues

31. This and a number of other cases currently with the Ombudsman's office raise issues about whether recent decisions by English Courts might be expected to have had a bearing on policy and practice in Scotland. While the English decisions themselves do not have direct application, the legal principles which they established and the developments which have flowed from them in England demonstrate that clarification on the issues of provision, assessment and decisions on NHS Continuing Care is necessary and important in terms of the Scottish guidance. The Ombudsman has raised this issue with SEHD who have indicated that they will be considering the implications of these judgements carefully as part of the review of Free Personal and Nursing Care currently being undertaken by them.

32. These cases have also illustrated the need for a clearer, more accessible and a more transparent process for assessing eligibility for NHS Continuing Care funding. This office has also raised these concerns with SEHD who have advised us that they acknowledge the procedural gaps identified in the current guidance and are seeking to address this issue in draft revised guidance which they are in the process of developing.

33. In light of both the review of the guidance and the implications of the English developments the Ombudsman will be sending a copy of this report (along with the other related reports) to the SEHD for consideration of the impact of the current guidance in individual cases.

20 June 2007
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Annex 1

Explanation of abbreviations used

Mr A	The aggrieved
Mrs A	The aggrieved's wife
The Solicitors	The Complainant (representing the Family)
The Family	Mr A's family
The Board	Fife NHS Board
The Adviser	Clinical Adviser to the Ombudsman
Consultant 1	The Consultant in charge of Mr A's care
SEHD	Scottish Executive Health Department
NHS QIS	NHS Quality Improvement Scotland
The Nursing Home	The nursing home where Mr A was resident after his hospital admission
The Hospital	Whyteman's Brae Hospital

Annex 2

Summary of legislation, policies, case law and reports considered

National Health Service (Scotland) Act 1978
Section 36 states:
(1) It shall be the duty of the Secretary of State to provide throughout Scotland, to such extent as he considers necessary to meet all reasonable requirements, accommodation and services of the following descriptions -
(a) hospital accommodation, including accommodation at state hospitals;
(b) premises other than hospitals at which facilities are available for any of the services provided under this Act;
(c) medical, nursing and other services, whether in such accommodation or premises, in the home of the patient or elsewhere.

Social Work (Scotland) Act 1968
Under section 12 A (which was inserted by the National Health Service and Community Care Act 1990) a Local Authority has a duty to promote social welfare by making available advice, guidance and assistance as appropriate (this will include the provision of residential and other establishments)

Community Care and Health (Scotland) Act 2002

Scottish Public Services Ombudsman Act 2002

MEL 1996(22)
Sets out the responsibilities of the NHS to arrange discharge and the criteria for eligibility for NHS funded Continuing Care. Issued by the then Scottish Office Department of Health (now SEHD).

SEHD Circular
No. SWSG10/1998
Scottish Office: Community Care Needs of Frail and Older People (Integrating Professional Assessments and Care Arrangements)

SEHD Circular
No. CCD 8/2—3
SEHD Circular: Choice of Accommodation – Discharge from Hospital

SEHD Letter
DKQ/Q44
Directorate of Service Policy and Planning letter to all NHS Chief Executives on 13 June 2003, outlining the process for handling Continuing Care funding complaints.

The Health Service Ombudsman for England
HC399 (2002 – 2003) & HC144 (2003 - 2004)
Reports on NHS funding for long term care

List of Case Law (and brief summary conculusions)

R v North and East Devon Health Authority ex parte Pamela Coughlan [2000] 2 WLR 622
The court found that a local authority can provide nursing services but that this is limited to such services which are provided as ancillary to the accommodation provided by the local authority in fulfillment of a statutory duty.
The court also considered the eligibility criteria for NHS funded care and noted that Health department guidance could not alter a legal responsibility under the National Health Service Act 1977. In particular it drew attention to a danger of excessive reliance in the Health department guidance on the need for specialist clinical input.
The court concluded that whether it is lawful to transfer care from NHS to local authority responsibility depends generally on whether the nursing services are incidental/ ancillary to the local authority provision and of a nature which the local authority can be expected to provide.

R (on the application of Maureen Grogan) v Bexley NHS Care Trust and Others [2006] EWHC 44
The court ruled that the eligibility criteria for NHS Continuing Care were unlawful as they contained no guidance as to the test of approach to be applied when assessing a person's health needs in determining eligibility.

Annex 3

Procedural difficulties and confusion arising from MEL 1996 (22)

1. The MEL was issued on 6 March 1996, more than 11 years ago. Much has changed in that period in terms of how the NHS is organised, how care is provided and the surrounding statutory and policy context. To take just one example, the coming into force of the Human Rights Act 1998 places a positive duty on public authorities to act in a way that is compatible with the rights conferred under the European Convention. The NHS Continuing Care cases reviewed in this office suggest that this Act may potentially have implications for the MEL beyond the procedural.

2. Given this background it is not surprising that complaints received in this Office show common themes of dissatisfaction associated with the process of being assessed for and obtaining NHS funded Continuing Care.

3. The lack of a formalised process for Continuing Care assessment means the public are often unable to obtain clear information about the qualification criteria for NHS funded Continuing Care. There is a lack of clarity about when a patient should be the subject of a multi-disciplinary assessment under the MEL. This assessment generally occurs at the time of a patient's discharge from hospital. Not every patient discharged will require to be assessed under the MEL but there is no clear guidance on how the decision on whether or not to assess is made. Decisions about whether patients need to be assessed for eligibility for NHS Continuing Care are properly made by consultants as part of the process of deciding whether they can be discharged from hospital. There is no formal requirement for such decisions to be documented and where documentation exists it tends to be sparse. This results in a lack of transparency and potential inconsistency in the decisions made.

4. The lack of a formalised process for NHS funded Continuing Care assessment also results in a lack of clarity about how somebody who is not being discharged from hospital can access the Continuing Care assessment process under the MEL. The NHS has moved to work more closely with local authorities on assessment of care needs. The MEL does not reflect any role for such activities in assessing the potential eligibility of those currently living in the community (rather than this being carried out by hospitals as part of their discharge procedures).

5. The fact that certain patients are not considered eligible to be assessed without being given any formal assessment results in confusion about the reasons for refusal of funding. The way in which the MEL functions is not always clearly communicated to families and they are often not provided with details on how to appeal and request a review of the decision to refuse funding. Furthermore, if somebody has not been considered as eligible to be assessed under the MEL, there is no automatic right of appeal and no formal way in which the family or the patient can request an official assessment.