



What was this meeting about?

We organised this workshop to:

- Explore together what shared care records are, and how they may improve mental health care
- Discover what different people think may be the problems of having shared care records and what may be some solutions
- Investigate who needs to do what next

Key points:

- Information capture should not be for the production of statistics at the expense of having a service user focus. (p2)
- A shared care record should assist the delivery of out-of-hours care, reduce the chance of crisis turning to tragedy and signpost who is delivering which intervention to whom. (p3)
- A shared care record should contain a free text component to allow a service user to input the information on an encounter that they believe is most important. (p3)
- Definitions of presenting problems should not only be about medical factors but should include social and lifestyle factors and what psychosocial/recovery approaches are being adopted. (p3)
- One of the most important pieces of information a care record should include is prescriptions. (p3)
- Access to individual fields within a record is an alluring option but system administration resources are limited so this might be hard to deliver. (p4)
- Out-of-hours and crisis intervention services should have access but this might be through being given a PIN to unlock the record. (p4)

Agenda

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| 2:30pm | Tea/Coffee |
| 3:00pm | <i>Welcome and Introduction</i>
Sheila Forbes
Aberdeen Mental Health Users' Network |
| 3:10pm | <i>What are we talking about sharing: electronic care records and the information core for integrated care</i>
Alastair Philp
Improving Mental Health Information Programme, ISD Scotland |
| 3:30pm | <i>Group discussion exploring:</i> <ul style="list-style-type: none">• What should a shared care record be for?• What key information must a shared care record contain?• Who should be allowed to access the shared information? |
| 4:30pm | Who needs to do what next? |
| 5:00pm | Finish |

Welcome and Introduction

Sheila Forbes, for the Aberdeen Mental Health Users Network, opened the meeting by welcoming participants. The Mental Health User Network is a resource that provides unbiased information on a range of topics that service users and professionals with an interest in mental health will find useful. Our role is very much that of being a facilitator. Through links with other organizations they aim to enable service users to access information, services and support and to promote good practice across all services. The Network provides regular newsletters that includes information about national and local developments that are important to service users.

Introducing the Improving Mental Health Information Programme?

Alastair Philp then introduced the Improving Mental Health Information Programme¹. The “*modern, responsive mental health services that meet individually assessed need*”, that the Scottish Executive want to see develop, can only be realized if we have better information to improve care. However, mental health information is currently weak & fragmented, particularly in primary and community care.

So an Improving Mental Health Information Project was established in 2001 with the following aims:

- Promote information sharing within care teams (in part through shared care records using a nationally-consistent information core)
- Encourage local use of the information thus gathered to improve mental health services by answering quality and service planning questions.
- Improve access to currently gathered nationally consistent information
- Help mental health information projects share knowledge

The project has produced a number of outputs including: “*Mental health in Scotland: information sources and selected insights*”², a review of the types of mental health information available in Scotland; the report of a consultation carried out by the Scottish Development Centre for Mental Health among mental health service providers across Scotland into their information needs³; a report of our first national meeting⁴; and notes on several workshops on information sharing and shared care records⁵.

Because nationally consistent information on encounters, and interventions delivered, in the community is particularly poor, we are developing an Information Core for Integrated Care (ICIC)⁶.

Questions and points arising

- Use of the term care recipient was felt to imply that a user of services was merely a passive recipient of care and did not have an important role in their own recovery. This was unfortunate since they should be seen as equal partners in defining the problem and agreeing on how it would be addressed.
- The profession of the service user should be noted
- We must beware of documenting the problem, and not solving it
- Key data that must be shared, particularly between psychiatrists and GPs, is prescriptions
- We need to change attitudes within the service and society so that labels do not stigmatise
- Need to persuade psychiatrists that they are only one part of the solution, and deliver only some of the important interventions
- Information capture should not be for the production of statistics at the expense of having a user focus. However we recognised that we do need statistics in order to demonstrate the need for more investment to improve services and to show what works (and what doesn't)

¹ See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=1354>

² See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=1554>

³ See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=1948>

⁴ See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=2270>

⁵ See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=1584>

⁶ See <http://www.isdscotland.org/isd/collect2.jsp?pContentID=1580>

Note of group discussion

We broke into small groups. Each group was asked to think of a shared care record as a house, e.g. with doors mediating access, windows being ways of looking in and rooms representing areas of particularly related information. We used this method to explore:

- What should a shared care record be for?
- What key information must a shared care record contain?
- Who should be allowed to access the shared care information?

Given the policy position of the current government we assumed for the purpose of this discussion that an electronic shared care record will come into being. The discussion was therefore restricted to exploring what issues had to be considered and how best a shared care record could be introduced.

What should a shared care record be for?

- Different things: joined up care is first and most important but also to generate information for quality improvement and service planning purposes. There was a general acceptance of the latter as long as information gathered was anonymous; although there was some cynicism expressed that this may be the main purpose of the project!
- To assist the delivery of out-of-hours care, to reduce the chance of crisis turning to tragedy and to signpost who is delivering which intervention to whom
- To document who knows about an admission or discharge and help others find out who need to know
- To allow the preparation of statistics on trends in care delivered and variations among teams or practitioners or client groups
- Should be to enable the best possible treatment to be devised and delivered, in collaboration with service users, for the benefit of the service user
- To allow medical staff to communicate and in particular to transmit prescriptions
- Should be about the service user, for the service user rather than for the care provider's benefit. However we need to be pragmatic and recognise that we need to work with the staff we have and therefore the system requires to offer them some benefits too (or it'll fail on the reef of cynicism).
- A benefit of shared care records would be sending appointment cards to the correct/ current address!

What key information must a shared care record contain?

- The structure should contain a free text component to allow the service user to input the information on the encounter that they believe is most important. The absence of a facility for service users to have their own controlled area for registering complaints, comments and to identify what works for them was also seen as reinforcing the medical model.
- However structure rather than freetext is used in most fields of the ICIC to allow read across from the ICIC to and from assessment and care planning packages. This is important to minimise the amount of duplication of data input by already harried staff. There is therefore a tension between ease of capture of information and useability and inter-operability once captured
- Action to take in case of a crisis. For example which out of hours services should be used based on past experience and user preference and how to contact them and others who would need to be informed.
- Care in the community resources used, or available to the individual
- Definitions of presenting problems should not only be about medical factors/illness/diagnosis but should include social and lifestyle factors and what psychosocial/social work/recovery approaches (including housing and employment) are being adopted. Information capture should support changing the care delivery model from a medical model of 'care and maintenance' to a more holistic 'recovery and rehabilitation' model. More social care/lifestyle factors than are currently offered on draft ICIC need to be available as choices.
- Prescriptions: one of the most important things the service users felt was missing from the draft ICIC was prescriptions. As it was pointed out, the inclusion of this would save both GPs and patients time by eliminating the need for visits to surgeries. it would also mean changes in medication would take effect more quickly.

- Admission and discharge dates (although this may be more appropriate for a specialist in-patient record such as the current SMR04 or its successor). Such information would be useful in determining whether admissions peak at times of staff holidays or where certain resources (e.g. day hospitals) are closed. We need stats on this...
- Whether a complaint has been lodged. The thinking here is that the more people are aware of a complaint, the more folk can work to resolve it. For example if a GP knew about a complaint in the specialist service she might be able to intervene.
- The information sharing model adopted should not merely reinforce current ways of working but allow development of new approaches. The care record must therefore document 'our whole lives and not just the acute periods of illness'

Who should be allowed to access the shared care information?

- There was a general agreement that service users, medical professionals etc. should have access to information on the file relevant to their professional interest with the service user having the right to decide who has access to their file.
- Access to individual fields with a record is an alluring option but system administration resources are limited so might be hard to deliver
- Psychiatrists, casualty doctors and Gps, partic around which medication a service user is on
- Service users should have immediate access rather than having to wait for weeks while records are reviewed and pages removed (intended to prevent the user from harm)
- Consents need to be more specific than blanket/general
- In general we were happy with the concept of team access. However not all are treated by teams (e.g. personality disorders) and the concept of teams is elastic
- Information must not only be collected and shared. It must be acted upon and generate positive action
- Out-of-hours and crisis intervention services should have access but this might be through being given a PIN to unlock the record. The service user might keep the PIN on their current voluntary 'service user card'. Care should be taken so that those with a history of mental health service usage are not denied access to appropriate services for their physical health complaints. Locums could be precleared for consent to view by the service user when their appointment was made.
- Carers should have controlled access
- Who will put the info in: care providers or admin staff. The former are busy and the latter scarce.

Who should do what next?

- IMHIP to consult more, particularly around lifestyle/social factors and interventions
- Need to develop electronic prescribing so that maintenance prescribing can be by GP under supervision of psychiatrist and errors can be prevented at pharmacy
- Investigate the use of PIN codes to control access of non-core staff to information