

Adult Care Information Network

"Mental Health - developing an information agenda in social care and health"

Cardiff, 16 June 09

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Introduction

The meeting was hosted by Howard Teague, ACIN Country representative, on behalf of Wales. The context for Workshops was set by presentations from:

- Netta Hollings, of The NHS Information Centre (who also presented on behalf of Tim Crosier of the Cabinet Office)
- Steve Luckham of the DH - South East
- Dr Les Rudd and Phil Chick, of the Centre for Mental Health Services Development (CMHSD) and National Leadership and Innovation Agency for Healthcare (NLIAH), part of NHS Wales
- Lorna Jackson for Lee Davies of NHS Scotland; Ruth Glassborow, and Paul Arbuckle of NHS Scotland

Additional material was contributed by Luke Ward of the Department of Health, East of England.

Headline Points

- How do we know that information is useful? – how do we know that existing policy is working? And how do we contribute to the development of policy that is evidence-based? Collections are often driven by the need to prove that policy is working, not to plan for the future/drive future policy - we should think about information needs during the development of policy
- Need to be clear what are the outcomes that policy seeks in MH? – more independent living? Reduced costs? Better knowledge? Early(ier) diagnosis? Development of services? Services are improving? Must include Information and measures on the experience of service users and whether care is improving their quality of life - the outcome at individual level, is it making a difference?
- What are the policy questions that information would need to answer? How do we deal with growing incidence of dementia in a rapidly ageing population, who will the carers be? What if the diagnosis rate increases? What if direct payments go up? What would be better outcomes for people? What services should be in place? How can we encourage Councils to place clients in better quality care? How good is our care? How effective? Is it getting better? What is the mental health 'gain' and degree of recovery (change over time)? What are the levels of user satisfaction & attainment of self determined goals?
- The value of data is in the capacity to analyse and use it. Information must help answer questions around: How will we know that a change will result in improvement? What change can we make that will result in improvement?
- Health and social care data definitions should be aligned - we need common data definitions & pro-formas compatible with multiple IT systems
- Need to consider the users of information – Wales intends to adopt the Dr Foster "Intelligent MH Board" (2007) and help Board information to focus on strategic goals, better questions and better governance
- Need to reflect more on what is meaningful data - what we are collecting and what it tells us, and how to link person centred outcomes - quality of life - to "clinical" data: instead of/as well as measuring the incidence of mental health conditions, could we collect SU info at CPA re what are the key 3 outcomes for the SU? So we could measure later whether achieved.
- Three types of outcome – how effective was intervention in terms of improved mental health; patient experience outcomes – how did it feel to be on receiving end of service; and outcomes re minimising risk. Perhaps a fourth type of outcome around whether person's individual goals were met?
- Could devote resources to speeding up progress of social care benchmarking etc so it converges with more advanced work in health sphere
- Could suggest that we develop the pilots in social care ahead of health even if data may not appear to be as good
- Could we have a UK-wide core minimum data set with different countries adding on their own additional requirements? – is there a will across four countries to work towards this?

Key messages from Policy

- The 4 countries are not “joined up” and have diverged in terms of policy: since devolution. Scotland has abandoned CPA (Care Programme Approach, an integrated care management system), England is focussing on enhanced CPA only, Wales has retained both standard and enhanced CPA, and NI uses care management approach with single assessment leading to a care package
- CPA originally coincided with Care in the Community policy and assumptions of cost savings as well as improved quality of life
- The Mental Health Minimum Data Set (MHMDS) initially developed to support monitoring of the mental health element of the then Government’s ‘*Health of the Nation*’ strategy in 1992
- The MHMDS became mandatory in 2003/4 to help monitor National Service Framework (NSF) implementation. This has created a potentially valuable information resource, linking info on care provided, in the community and in hospital, with anonymised individual patient records. The MHMDS can be used to answer policy questions, not only about what services are being used, but also about whether they are helping to improve people’s lives
- In England the policy changed in November 2008 and will reduce relevant numbers of people on CPA by ¾. The focus is to be on those with more complex needs (CQC: receiving care from at least two different professional groups) and simplify/reduce form-filling and the “burden of bureaucracy”
- New policy has focussed on areas such as personalisation of care and development of direct budgets, which have implications for information. However, personalisation appears lower on the agenda for some groups such as mental health users and older people
- At community level and “on the ground”, health and social services teams have worked jointly in mental health for some time, and social workers are already accessing NHS data on users. But information systems for health and social care remain un-integrated. Some organisations such as Care Trust have to make similar but different information returns, ie for health and for social care (the RAP), as these are not joined up. Should local authorities convert to NHS systems and who would fund the cost?
- There is huge resistance to joining up health and social care information systems and a challenge around joint ownership ie joint **health and social care** targets
- Joint Strategic Needs Assessment (JSNA) in England targets health and social care with joining up to assess needs and feed this into commissioning and Local Area Agreements (LAAs), to enable better outcomes for users
- Need to be clear what are the outcomes that policy seeks – more independent living? Reduced costs?
- Concerns were expressed around the impact of policy seeking to “reduce the burden” and make data collection less onerous, which is effectively to “dumb down” the information available
- Policy often demands short timescales in which to show change eg England’s Dementia Strategy seeks to show improvement by 2011

Key challenges for information

A key question is, how do we know that information is useful? This question faces in two directions – how do we know that existing policy is working? And how do we contribute to the development of policy that is evidence-based? It is essential that information collection and policy are aligned more quickly – for example, the NSF for Mental Health set up crisis resolution teams, but no records were collected of the number of admissions that they handled, so no deductions cannot be made about the usefulness of this policy.

There is a lack of data being collected around **social care aspects of** mental health – a key source being HoNOS scores. Through the Care programme Approach in Mental health, data should have been collected since 1999 on employment and accommodation for users of mental health services. This is information is now being required for key indicators for national PSA targets in England and should be easy to source – but the data quality appears patchy. Also, for PCTs, this is “tier 3” information (less frequently collected) so may be given relatively lower priority and attention. Data on mental health and Learning disability indicators is to be published in England in September 2009.

There is a need for alignment of standards in NHS and social care – and England has an Information Standards Board. In terms of developing a mental health MDS, teams are already working separately to develop data sets (eg for **CAMHs?**) and some are now too far advanced for it to be feasible to adopt one top-down data set. But many data sets overlap.

Netta Hollings presented on The Information Centre (IC)’s **comprehensive review of Mental Health (MH) Information** in the summer and autumn of 2008. This had not been made fully public. It had concluded that **much of the impact of policy cannot be measured**. It had made recommendations on the areas that collection of data needed to cover, being:

- Payment by Results
- Clinical Engagement
- Outcomes
- Improving Access to Psychological Therapies
- Child and Adolescent Mental Health
- IT Systems
- Governance
- Data Standards
- Inequality monitoring

It had also made important recommendations around mapping and aligning data definitions in Social Care:

- In the short-term that investigations be carried within the NHS IC to (a) bring together definitions of data items required in the RAP returns, and (b) find out if Care Trusts can be permitted to submit RAP returns.
- In the long-term and as part of the NASCIS project, health and social care data definitions should be aligned
- Inclusion of RAP data items in MHMDS (MH Minimum Data Set) to be investigated.

A problem has arisen in England around who should decide on data definitions and standards. The Cabinet Office has permitted individual Councils to decide on their definition of complex needs and therefore who should be on enhanced CPA. This will create variance. England will lose the capacity to collect information on the previous cohort of people on CPA as the only coding being collected will now be the enhanced level of

CPA. Local discretion is to be used to plan the care in England of the (majority of) mental health service users who are not placed on enhanced CPA.

Steve Luckham presented on the **National Dementia Framework** in England and **Dementia Metrics Framework**. Key challenges for information concerned:

- How to define dementia – is this a clinical, or care manager/social worker diagnosis?
- What are the prevalence rates? (information from POPPI and the Alzheimer Society)
- What is the picture of dementia – and what do we want it to be? Eg do we want to know the numbers living in residential care – or the numbers living independently?
- Or is the big question around the efficiency of provision? (eg does community care cost more?)
- Establishing the current baseline from which to measure improvement – as there is limited dementia specific data – need to agree what is to be collected and identify gaps for example, carers of people with dementia
- Age bands are important and may modify our interpretation
- What are the policy questions that information would need to answer? Is the National Dementia Strategy (NDS) being implemented? How do we deal with growing incidence of dementia in a rapidly ageing population, who will the carers be? What if the diagnosis rate increases? What if direct payments go up? What would be better outcomes for people? What services should be in place? How can we encourage Councils to place clients in better quality care?
- What should policy outcomes be – better knowledge? Early(ier) diagnosis? Development of services? What information do we have to feed indicators to measure improvement?
- Dementia data is a non-mandatory part of the RAP so Councils do not necessarily complete this
- How to get the whole picture – Council clients plus those who self fund care
- How to eliminate double-counting – could perhaps sample on one day only
- Data quality improvement – some of the data is inconsistent: CQC think the answer is interrogate and use it – then it will improve
- How to develop a culture of self-responsibility for data.

Discussion, questions and summarising emphasised the **challenges** of:

- Agreeing consistent data sets and linking up information systems;
- The tension of agreeing data sets that can measure the current picture, as well as improvement and quality. What is the priority?
- Standardising approaches across the 4 countries to facilitate comparison
- Data to enable targetting of inspections as well as improving outcomes
- Data quality – eg problem of incompleteness of RAP; last year Wales did not publish carer data as it was not of sufficient standard and there were issues around the definition of carers
- Developing “smarter”, “leaner” measures
- Using the data we have eg getting access to GP data
- Why can't we focus on a standard approach, on one tool – eg one dataset, unified assessment, a CPA dataset

- Understanding what are the benefits and purpose of information – eg enabling and measuring service improvement, policy-making, better knowledge? measuring improvement? ensuring equalities? etc
- What (information framework etc) needs to be mandatory?

For Wales, **Dr Les Rudd and Phil Chick** presented on developing **mental health & social care 'intelligent' targets and outcome measures** in Wales. They noted challenges for policy around:

- The need to operationalise Strategy and pilot tools
- The co-existence of dementia with other long-term conditions
- Enabling real integrated working and joining up central and local government
- The need for a policy shift to focus on “total place” and join up all public spending (12 pilots in England)
- High-level KPIs – there are datasets for components of service rather than at a high level
- Dementia is a “hidden iceberg” – probably only 20% has been diagnosed
- Need to encourage hospital wards to check with all admissions whether the admitted person has dementia (scans and physical symptoms) – hospital general wards are unfamiliar with dementia
- Hospital admission is unsettling and this can make dementia symptoms more manifest
- This triggers more admissions to residential care – instead, need to encourage people to return home with appropriate support
- The desire to drive up compliance with planned care package to 100%.

On outcome assessment of mental health services, Wales wants to establish:

- What is the use of our MH services? By whom, for what, where, how much?
- How good is our care? How effective? Is it getting better? What is the mental health 'gain' and degree of recovery (change over time)? What are the levels of user satisfaction & attainment of self determined goals?
- How do outcomes compare with other places? On quality & safety?

Challenges for information currently are:

- Lack of consistency in the use of terminology and definitions
- Lack of standardisation in data collection - data may not be recorded in a consistent manner
- Resistance to standardisation - centralisation
- Data may not be collected
- Data may be collected in some areas of Wales and not others
- Data may be collected but not routinely reported
- Bureaucratic systems
- Organisational barriers exist – lack of integration
- Lack of joint NHS/Social care targets
- Need for training on CPA & outcome focussed care planning
- Need for dedicated resources of people and IT – supportive infrastructure
- We need common data definitions & pro-formas compatible with multiple IT systems coordinated via data warehouses, rather than a single IT solution

- Need to consider the users of information – Wales intends to adopt the Dr Foster “Intelligent MH Board” (2007) and help Board info focus on fewer and more strategic KPIs focussed on strategic goals – thus enabling better questions and better governance
- Often, we collect so much data but lack the capacity to **analyse** it.

The **WAG** has committed to a national standardised Data Set(s) for Wales Mental Health Services. However, this will be less extensive than England’s. The CMHSD/NLIAH recommended (2008) a three-tier system for information with **intelligent targets**:

- 1. National high level KPI’s (Intelligent Targets & Dashboard)
- 2. Organisational-level common data set (OCDS)
- 3. Individual client level common data set (ICDS) – process & outcome focus – a *minimum* Data Set.

There is a whole system model that aims to find out what we need to do for people and whether we can deliver this/how well, eg services for depression. They aim to use the evidence base from NICE etc to intervene at key points so as to have impact and essentially to:

- Improve the reliability of care in Wales
- Raise standards of care in Wales

To gain ownership and secure (clinical) change with a greater focus on quality, there is a focus on the process and model of change with Greehalgh criteria – these are:

- It must have clear relative advantage
- It must have compatibility with the user’s values and ways of working
- Complexity must be minimised
- Users will adopt more readily if innovations allow trialability
- There must be observability, that is it must be seen to deliver benefit
- Reinvention is the propensity for local adaptation.

Essentially, this is a Plan-Study-Do model with straightforward questions:

- What are we trying to accomplish?
- How will we know that a change will result in improvement?
- What change can we make that will result in improvement?

These are questions that the information must help answer.

Scotland has developed a Mental Health Benchmarking Project with a Mental Health Benchmarking Implementation Group – MHBIG. This is working to recommendations around aligning definitions and improving the ways in which NHS Boards use information:

- To develop and implement joint mental health service definitions and functions
- To align costs with service definitions and functions
- To work with NHS Boards to develop the benchmarking mandatory measures, based on the balanced scorecard approach
- To provide information that will support measurable improvement in NHS Boards

Scotland has adopted a balanced scorecard approach, with information on 22 indicators on cost, patient quality, efficiency and the future. Noting that the main source of data currently is hospital data, they have developed a 3-phased approach:

- Phase 1 Data available: Data and data sources being agreed

- Phase 2 Further refinement of definitions and data /data sources – new data
 - Phase 3 Further development of definitions and data /data sources – methodologies
- As in Wales, the aim is to make intelligent use of targets and start with the data we have, so as to find out if we are making an improvement.

The **Scottish Mental Health Collaborative** aims to make extensive use of data within the improvement agenda. Reducing psychology re-admissions, support for dementia (numbers on QOF register), prescribing for depression, will all contribute to delivery of national targets. Skilling up front line staff to use information to deliver continuous improvement is planned through:

Understanding how well current system/processes work	Statistical Process Control; Process Mapping; Root Cause Analysis; DCAQ; Patient Experience feedback; Measurement/Data
Design a Better System	Evidence based practice; Value Streaming; DCAQ; Visual Management/Behavioural Sciences; Patient Experience Input
Implement the Change	PDSA; Human Dimensions of Change
Evaluate the Change	Outcomes data; Measurement; SPC; PDSA; Patient Experience Feedback

The assumption is made that the problem is poor systems rather than people. Tools are being tested and mainstream management improvement theory adopted. It was emphasised that it is important to understand variation and not jump to the wrong conclusions; and important to look first at areas that will have the largest impact. Tools can be used to develop understanding of why some delivery (eg GP practices) are good, and spread the good practice. The over-arching aim is to present data so that people will USE it.

Key issues from the workshop discussions

The quality of policies:

- Challenge of definitions/language used and who owns them (is this policy-makers?) – eg should depression be included in mental health?
- We should think about information needs during the development of policy – evidence-based policy largely led by pressure groups such as MIND.
- There are fundamental disconnects between central government agendas eg personalisation/personal budgets/payment by results/efficiency/saving money.
- Tension exists in mental health between public safety/suicide risks and drive for independence and improved quality of life.
- **Some policies are close to mantras eg “choice”**
- How does policy recognise diverse and cyclical nature of MH? What is incentivised? Eg are GPs being incentivised to keep people on their registers?
- What are the key outcomes to aim for eg enabling more people with mental illness including dementia, to remain independent/return home?
- Can/should we have tariffs in mental health?

The 4 countries' policies:

- Challenges for the 4 countries are similar, eg incidence of mental illness, and still need to join up H&SC and reduce duplication of recording
- Policies have diverged: Scotland has abandoned CPA, (as an integrated care management system) England is focussing on enhanced CPA only, Wales on standard + enhanced, NI uses care management approach with single assessment leading to a care package.
- Value in using ACIN to compare and learn from each other which approach is working best

The position of social care in relation to health:

- Social care needs more "voice" – we need to challenge "silo" thinking through which social care gets added ("and social care") but remains separate.
- Health "voice" dominates especially at government/central levels
- Powerful silos of Health versus Social Care in each country
- Local Authorities (eg through SOAs in Scotland) are more independent of the centre than are local health authorities/boards, so it is harder to impose data requirements
- There is a risk that the social care element in mental health is becoming marginalised – mental health is increasingly governed by legislation and statutory duties with an emphasis on medicalisation – this can militate against integration of H&SC and reduce the social care contribution.

Language: is not neutral - mental "health" positions mental health as part of health – rather than as part of well-being generally

Values: There are values in the information eg around the value of integration and of patient focus.

Challenges for information:

- Collections are often driven by the need to prove that policy is working, not to plan for the future/drive future policy
- How do we use info to drive future policy and the "outcomes we want to see" in MH?
- What is meaningful data? - what are we collecting and what does it tell us? How to link person centred outcomes - quality of life - to "medical" data - instead of/as well as measuring the incidence of mental health conditions, could we collect SU info at CPA re what are the key 3 outcomes for the SU? So could measure later whether achieved.
- Mental health service users include those who cannot articulate their care needs, posing some special challenges for information.
- There is basic patient information that is generic across all health care and social care provision – but there are additional mental health specific information needs.
- Mental Health is not one approach – different issues for Dementia versus CAMHS versus adult services. Specialist mental health assessment differs from generic integrated assessment models. Dementia sits much more closely with the generic health and community care approach and mainstream chronic conditions management.

Outcomes data:

- Three types of outcome – how effective was intervention in terms of improved mental health; patient experience outcomes – how did it feel to be on receiving end of service; and outcomes re minimising risk.
- Is there a fourth type of outcome around whether person's individual goals were met – or is this integral to improved mental health and patient experience?
- What are the outcomes to measure in MH? In Mid Staffs there were issues of mortality rates and emergency pathway; in mental health, high mortality, suicides, homicides, admission rates. But a seriously deprived area could tick all of these and yet have good mental health services.
- Two ways of measuring outcomes at population level – aggregating up from individual patient outcomes – but does public safety need to be measured at aggregate level?
- We could start collecting data on the outcomes desired by mental health service users quickly as we already know what their top 3 preferences are: accommodation, social networks and **love**.

Gaps in Information:

- Information on carers: IC are piloting "Carer experience survey"
- Information on care self-funders
- People ineligible for social services care who are not therefore registered
- Ethnic minorities and others for whom there may be social taboos against registration
- Social rather than clinical (diagnosis) information
- Information and measures on the experience of service users and whether care is improving their quality of life - the outcome at individual level, is it making a difference?

Sources of resistance to information capture

- Political – limitations on £ and eligibility (criteria)
- DH requirement that unmet need be not recorded (1990 Community Care Act)
- Sharing data – changes in clinical diagnosis not shared with social services.
- Stigma of declaring mental health problems/ loss of independence.

What is the purpose of benchmarking indicators?

- Not an end in itself – is just an indicator of where there might be opportunities for improvement – but need to use indicator to focus further questions as might be good reasons for variation
- Benchmarks can tell you how well doing – but not what you should be doing.
- Standards can tell you what should be doing?
- Danger that benchmarking, if used wrongly, just drives everyone to the average. Need to focus on best practice benchmarking.
- Benchmarking needs a relevant peer group
- Is the key about benchmarking process rather than benchmarking indicators?
- There are some indicators where we don't know what the performance should be – but can compare between different areas to establish where there is variation and then understand that variation.
- There will be some commonality between UK countries around what would be included as core data and some difference around political priorities

- Must adjust any comparative data for deprivation, socioeconomic issues etc. For England and Wales, **MINI** needs updating – is there an opportunity to do this as a four country piece of work?

Some practical suggestions:

- Could devote resources to speeding up progress of social care benchmarking etc so it converges with more advanced work in health sphere
- Could suggest that we develop the pilots in social care ahead of health even if data may not appear to be as good
- Need to promote mental health and social care, raise profile – what “hooks” could we use? Perhaps efficiency and preventative agendas – SC preventative work can reduce hospital costs.

A UK minimum data set?

- Sometimes the four countries are collecting similar information and calling it different things
- Could we have a core minimum data set with different countries adding on their own additional requirements? – for ease of comparison
- Why is it so important to get an MDS that IS “minimal” even WITHIN our country?
- A UK Wide Core Data Set – is there a will across four countries to work towards this?
- Political dimensions - countries will only align on issues where meets all their agendas
- What is our aim/end point – information that tells us whether interventions are contributing to mental health gain; need to include both professionally assessed outcomes and service user assessed outcomes, and what interventions delivered that outcome.
- Which data set(s) to build on? - view from some that England’s Mental Health Minimum Data set lacks diagnostics and outcomes data

Summary

- Challenges for the 4 countries are similar but policies have diverged
- There remains huge resistance to joining up health and social care information systems
- **Much of the impact of mental health policy cannot be measured** as there is insufficient data
- Concerns were expressed around the impact of policy seeking to “reduce the burden” which reduces the information available
- Policy often demands short timescales in which to show change eg England’s Dementia Strategy seeks to show improvement by 2011
- There is limited dementia-specific data, hence a need to agree what is to be collected and identify gaps for example, so as to establish the current baseline from which to measure improvement
- Policy needs to recognise the diverse and cyclical nature of MH
- Need to promote mental health and social care, and raise profile
- It is essential that information collection and policy are aligned more quickly

- There is a lack of data being collected around **social care aspects of** mental health
- Through the Care programme Approach in Mental health, data should have been collected since 1999 on employment and accommodation for users of mental health services – this data is now being published and data quality appears patchy
- Wales is developing a three-tier system for information with intelligent targets
- Scotland's Mental Health Benchmarking Project has adopted a 3-phased approach to data, building out from the data available to the data that is wanted.
- The Scottish Mental Health Collaborative aims to make extensive use of data with a variety of tools and techniques for use in the front line, to drive the improvement agenda
- We need to agree consistent data sets and link up information systems; but there is a tension in agreeing data sets that can measure the current picture, as well as improvement and quality
- We need to understand what are the benefits and purpose of information – eg enabling and measuring service improvement, policy-making, better knowledge? measuring improvement? ensuring equalities? Etc
- Three types of outcome – how effective was intervention in terms of improved mental health; patient experience outcomes – how did it feel to be on receiving end of service; and outcomes re minimising risk. Perhaps a fourth type of outcome around whether person's individual goals were met?
- Benchmarking indicators: not an end in itself – just an indicator of where there might be opportunities for improvement – but need to use indicator to focus further questions as might be good reasons for variation
- There is value in using ACIN to compare and learn from each other which approaches are working best

Next steps

- Coordinating group of country representatives would meet to review the day and actions proposed, and plan future programme
- Report to be prepared
- Report and full event materials to be posted on the ACIN website

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Report V1

Acronyms and sources

CHP	Community Health Partnership (Scotland)
CPA	Care Programme Approach
CQC	Care Quality Commission
CRILL	Capturing Regulatory Info at Local Level
CSIP	Care Services Improvement Partnership
HoNOS	Health of the Nation Outcome Score
H&SC	Health and social care
ICDS	Individual-client-level common data set
JSNA	Joint Strategic Needs Assessment
LAA	Local Area Agreement
LHBs	Local Health Boards?
MHBIG	Mental Health Benchmarking Implementation Group
MHMDS	MH Minimum Data Set
MINI	? (p10)
NASCIS	National Adult Social Care Intelligence Service
NDS	National Dementia Strategy
NI 130	People on direct payments/given personalised budgets
NLIAH	National Leadership and Innovation Agency for Healthcare, part of NHS Wales
NSF	National Service Framework
OCDS	Organisational-level common data set
POPPI	Projecting Older People Population Information System www.poppi.org.uk
PSA	Public Service Agreement
PWD	Persons with dementia
QOF	Quality and Outcomes Framework (for GPs)
RAP	Referrals Assessments & Packages/Practice of Care (ASC)
SC	Social care
SOA	Single Outcomes Agreement (Scotland)
UA	Unified Assessment
VPN	Valuing People Network
WISMAT	Substance Misuse...?

Sources:

<http://www.ic.nhs.uk/services/mental-health/information-review>

www.ic.nhs.uk

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www.ic.nhs.uk/acin

Appendix One **to add – final programme**