

Integrated care for people with LTNCs

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Evidence review on outcomes for service users

- ◆ Existing evidence base largely about integration of provision for older people
- ◆ Lots of information on process issues
- ◆ Tends to be about policy and structure issues
- ◆ Less on individual practice issues
- ◆ Little on outcomes for those on the receiving end



Findings from our review of evidence

- ◆ 2,552 publications identified by electronic and other searches
- ◆ 5,733 selected as potentially relevant
- ◆ 114 of these looked like evaluations
- ◆ Read all these
- ◆ 68 publications included for review
- ◆ 50 separate studies
- ◆ 48 different models of integrated care

Data extracted from evaluations

- ◆ Mortality
- ◆ Hospital admission
- ◆ Clinical outcomes
- ◆ Disability / impairment
- ◆ Mental health
- ◆ Coping or stress
- ◆ Use of or contact with services
- ◆ Costs to health services
- ◆ Costs to social care services
- ◆ Costs to patients or families
- ◆ Quality of life measures
- ◆ Patient view of model of care
- ◆ Impact on family/carers
- ◆ Patient/carer expressed need
- ◆ Social outcomes
- ◆ Knowledge of condition
- ◆ Staff views
- ◆ Communication in team or to patient

Outcomes reported

Use of or contact with services	21
Patient's view of model of care	18
Disability/impairment	17
Clinical outcomes	15
Quality of life	15
Mental health	11
Impact on family/carers	8
Costs to health service	8
Hospital admission	6
Communication in team or with patient	5
Patient or carer expressed need	4

Knowledge of condition	4
Social outcome, e.g. education, employment	3
Staff views on model of care	3
Mortality	3
Costs to patients or families	2
Coping or stress	1
Costs to social care services	0
Other	6

Access to or use of services

- ◆ A key outcome for integrated care?
- ◆ 21/50 studies reported this outcome
- ◆ Little consistency of outcomes
- ◆ Two good quality studies show no effect for patient information/education
- ◆ Other studies of multi-disciplinary teams, nurse specialists, and other forms of integrated care show small effects but these are not consistent across studies and tend to be short-lived

Service users' views

- ◆ 18/50 studies reported this outcome
- ◆ Only one of these offered any real comparison between integrated care and anything else
- ◆ Of four service user view 'domains' tested, only one was significantly different for those receiving this model of care (home-based vs hospital-based treatment)
- ◆ HOWEVER, this was continuity of care!
- ◆ Overall, service users are positive – but might this just be gratitude at getting *any* service?

Quality of life

- ◆ 15/50 studies reported this outcome
- ◆ 9 of these were RCTs
- ◆ So most robust evidence base so far
- ◆ 6 RCTs show no increase in quality of life for those receiving a model of integrated care
- ◆ 1 RCT of self-care advice for MS showed change in mental health and vitality
- ◆ 1 RCT of MD home care for MS showed change in overall mental and physical health-related quality of life
- ◆ 1 RCT of patient education and health promotion for PD showed change in 'self-efficacy'

But ...

- ◆ Poor studies
- ◆ Lack of measures before intervention
- ◆ Use of non-validated measures
- ◆ Inability to find data for study showing greatest effect



So what is going on here?

- ◆ Anything is better than nothing?
- ◆ Small numbers and poorly designed studies?
- ◆ Is demonstration of ‘conventional’ impact essential?
- ◆ If not, then we at least need to say something about cost – almost totally missing from the evaluations
- ◆ Are we asking the wrong questions?
- ◆ Are we measuring the wrong outcomes?
- ◆ What about empowerment, sense of worth, ability to make sense of one’s condition?

What do service users say?

- ◆ They want
 - ◆ Prompt diagnosis
 - ◆ Information and support
 - ◆ Person-centred care and choice
 - ◆ Flexible responsive services
- ◆ Delivery of a 'seamless' service
- ◆ How do any of these relate to existing outcome measures?



Is there a way forward?

- ◆ Better understanding of what *really* matters to service users
- ◆ Use that understanding to design outcome measures that are *appropriate*
- ◆ Implement those outcome measures at very first contact with service users and throughout
- ◆ Commission some robust research!



Case study phase

- ◆ Aims
- ◆ Data collection and analysis
- ◆ Some early observations (with a health warning!)

Case study phase

Aims

In-depth case studies in six neurology service systems to:

- ◆ identify the key indicators of good quality, integrated service provision
- ◆ understand its impact on service users and their families or carers

Case study phase

Data collection

- ◆ Interviews with PCT leads
- ◆ Observation of LIT meetings
- ◆ Key documents
- ◆ Interviews with staff across system
 - ◆ Health
 - ◆ Social Care
 - ◆ Independent Sector
- ◆ Interviews with people with LTNCs

Case study phase

Analysis

- ◆ Data management using Framework and MAXQDA
- ◆ Regular researcher meetings to discuss emerging issues

Not yet complete – following observations come with a health warning!



Interviews with staff

Interviews with staff

- ◆ Extent and nature of integration (at different levels)
- ◆ Commissioning structure and approach to implementation
- ◆ Service structure
- ◆ Barriers and facilitators to integrated working



Interviews with staff

Extent and nature of integration

- ◆ Integration interpreted and executed differently in different areas
- ◆ Not possible simply to compare ‘integrated’ and ‘non-integrated’ sites



Interviews with staff

Approach to implementation

- ◆ NSF generally well received
- ◆ Local Implementation Teams
- ◆ Interruptions

Factors influencing effectiveness

- ◆ Range and seniority of members
- ◆ Effectiveness of wider decision making structures
- ◆ Ability to maintain continuity

Interviews with people with LTNCs:

Asked about different elements of continuity*

- ◆ Longitudinal continuity
- ◆ Relational, personal and therapeutic continuity
- ◆ Flexible continuity
- ◆ Communication continuity
- ◆ Continuity of social context
- ◆ Long-term continuity

* Freeman, G., Shepperd, S., Robinson, I., Ehrich, K. and Richards, S. (2001) *Continuity of Care: Report of a Scoping Exercise for the NCCSDO*, London: National Coordinating Centre for Service Delivery and Organisation.

Models that appear to promote continuity

1. Clinical Nurse Specialist

- ◆ Expert key worker
- ◆ Accessible
- ◆ Whole picture

2. Community neuro-rehabilitation (and condition specific) teams

- ◆ Pool and improve access to specialist knowledge
- ◆ Flexible and responsive
- ◆ Whole picture

1. Clinical Nurse Specialist

Case example 1

MS Nurse Specialist as expert key worker

‘... when the MS nurse was there, you got one person. If you had any problem, wanted anything sorting, you just talked to her and she’d organise it, you know. Changing your prescription for the pills, you know, she could get you an appointment with the Neurologist ...’

(ASU03)

1. Clinical Nurse Specialist

Continues:

'And how important is the MS Nurse? I mean ...?'

(interviewer)

'Very. Very important, yeah. She really is, 'cause she's got the knowledge to be able to talk, and she has the time, so you have an hour appointment with her. And that's really important.'

(ASU03)

1. Clinical Nurse Specialist

Promotes different elements of continuity:

- ◆ Relational
- ◆ Longitudinal
- ◆ Communication – informational and cross boundary

Facilitates access to a complex system

BUT

Coverage is patchy and individual nurses are overstretched

2. Community neuro-rehabilitation (and condition specific) teams

Case example 2

PCT provided neuro-rehab team based at a community hospital:

- ◆ MDT (cross sector)
- ◆ Key worker system
- ◆ Open referral
- ◆ Long term focus (not time limited)

2. Community neuro-rehabilitation (and condition specific) teams

Promotes long-term and flexible continuity:

*‘So, for example, next week, I normally have physio with the X Team on a Wednesday and a Friday... is the norm. I’m unable to do Wednesday, so they’re seeing me Tuesday’
(CSU03)*

2. Community neuro-rehabilitation (and condition specific) teams

Impact on people's lives:

Without the X Team “[m]y quality of life wouldn’t be like it is now. I mean, my quality of life is not great, but it’s a – but it would be the pits”

(CSU05)

2. Community neuro-rehabilitation (and condition specific) teams

Promote different elements of continuity:

- ◆ Communication – informational and cross boundary
- ◆ Flexible (relates to social context)
- ◆ Long-term

Meet NSF QRs

BUT

Not everyone has access to such a service:

- ◆ Pathways
- ◆ Capacity



Conclusions

- ◆ Early stage of analysis
- ◆ Implementation appears to be slow
- ◆ Some high quality services clearly valued by people using them
- ◆ Access, pathways and capacity key

Much more to learn from the data!