Research and Clinical Practice: how to reap the benefits

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This presentation is about

• Undertaking psychosocial (non pharmacological) research within the NHS infrastructure – sometimes called clinical research or applied research

• The overall aim is to enthuse you to engage in this increasingly common form of research

• I will use examples from my own research portfolio to illustrate what I have learnt over time and identify how we might move forward together with this important agenda
What are the known benefits of clinical research?
But what are your experiences: positive and not so positive.......
What might be the pros and cons of getting involved?

<table>
<thead>
<tr>
<th>Pros</th>
<th>Cons</th>
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<tr>
<td>Funding to NHS from recruitment</td>
<td>Meeting recruitment targets</td>
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<td>Opportunity to delivering new innovations/learn about new ideas</td>
<td>Taking delivery demands into consideration in clinical workloads</td>
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<td>Measuring the impact of innovations/treatments</td>
<td>Workforce gaps: who is going to take the measurements?</td>
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<td>Learning research related skills</td>
<td>Having to do more in less time</td>
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The reality is a series of benefits and trade-offs – we want to maximise the benefits.
Example 1: Post diagnostic interventions and support for people with dementia: new territory for services

Research and Service Questions
What do people want?
What is beneficial and affordable?
Who should provide and for how long?
Also new territory for R&D departments within trusts

• How to recruit people post diagnosis to take part

• How to take outcome measures from people with diminished cognition – also issues of capacity

• How to organise delivery of psychosocial interventions for testing

• How to maintain intervention delivery over time
The Valuing Active Life in Dementia (VALID) research study is funded by the National Institute for Health Research’s Programme Grants for Applied Research Programme and is a partnership between North East London NHS Foundation Trust and University College London, University of Sheffield, University of Hull, Radboud University of Nijmegen, University of East Anglia, University of Manchester, Swansea University, Kings College London and Dementia UK.
The VALID programme aims to adapt, develop, evaluate and implement an occupation based intervention (COTiD-UK) which will promote independence, meaningful activity and quality of life for people with dementia and their family carers living in the community.
• Dutch intervention and training materials translated
• 44 occupational therapists trained by Maud Graff (original author)
• Intervention implemented with 130 people with dementia and their family carer (dyads) and amendments made
• Randomised controlled trial conducted with 480 dyads
Some of the challenges

<table>
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<th>Trusts</th>
<th>University</th>
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<tr>
<td>Recruitment and retention of:</td>
<td>Spread of sites across England – Hull to Cornwall</td>
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<tr>
<td>• Research sites</td>
<td></td>
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<tr>
<td>• Occupational therapists as intervention deliverers</td>
<td>Maintaining momentum at sites – recruitment and intervention delivery</td>
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<td>• People with dementia and their carers</td>
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<tr>
<td>Supporting the costs of intervention delivery</td>
<td>Maintaining intervention fidelity – need for on-going support</td>
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<td>Supporting the practicalities of intervention delivery – releasing staff</td>
<td>Methods of assessing fidelity – session recording</td>
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<tr>
<td>Ethical and practical challenges of recruiting people with dementia as research participants</td>
<td>Creating dementia friendly research materials/ information</td>
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Implementing VALID: the specific challenges for clinical occupational therapists

- Generic versus profession specific roles
- Procedural versus person centred intervention
- Changing practice
- Peer support and supervision
- Managerial support / protected time
Journeying through dementia: another example of an intervention designed to promote living well post diagnosis

Mountain GA and Craig C (2012) what should be in a self management programme for people with early stage dementia? Aging and Mental Health, 2012, 16(5)

Journeying through dementia: intervention delivery

- Intervention content driven by topics identified by people living with dementia; understanding dementia, rethinking dementia, living with dementia, relationships, keeping mentally well, experiencing well-being, dementia and daily living, keeping physically well, building and developing skills, keeping connected, maintaining a sense of self, planning for the future

- Facilitated by trained and supervised grade 3 or 4 NHS staff and supervised by more senior clinicians at site
From local to population based study

- Randomised controlled trial funded by NIHR HTA
- 12 study sites; Sheffield, Nottingham, Hull and others
- Intervention delivery commenced early 2017 and will complete autumn 2018
- Recruitment target 486
Some of the on-going challenges (from my perspective!)

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<tr>
<td>Identifying funding to deliver the intervention – excess treatment costs</td>
<td>Identifying sufficient sites willing to participate</td>
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<td>Identifying intervention facilitators and supervisors</td>
<td>Ensuring all sites have a trained research and delivery workforce which is then maintained</td>
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<td>Recruiting to a group intervention for people with dementia</td>
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<td>Balancing the demands of delivery with other clinical demands</td>
<td>Encouraging sites to collect and maintain data as requested – including records of intervention delivery</td>
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<td>Balancing the demands of this study with the benefits of engaging with new studies</td>
<td>Identifying who to communicate with about different issues</td>
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Learning transferred from VALID to Journeying through Dementia
How to involve people with dementia in all aspects of a large psychosocial study

Creating dementia friendly resources

Recruitment strategies and rewards

Methodology: fidelity, qualitative etc
Example 2: telehealth for people with long term conditions (CHF/ COPD)

http://www.trialsjournal.com/content/15/1/313

Study one: a pilot trial of a telehealth device for people post acute admission for COPD

‘Opportunistic study’ funded by South Yorks CLAHRC

- Clinician delivered intervention at one Trust – using technology Trust already had invested in

- Clinicians asked to reduce post admission visits to those with the technology

- Clinicians also expected to collect outcome data in ways dictated by the research
What could possibly go wrong...

- Technology availability and infrastructure inadequate at the time

- Focus on one site only – research highly vulnerable to staff turnover

- Staff not previously involved in research – lack of understanding of need to adhere to protocols

- Overburdened clinical staff asked to collect additional data
Study 2; mainstreaming assistive living technologies (MALT)

- Study which examined issues of implementing telehealth in practice and the associated costs and outcomes.

- Key to the research was the grass roots involvement of clinicians and patients

- Found that the key issues were staff and patient acceptance and that sustainable business models are essential
**Pre requisites - trusts**

- An infrastructure which includes support for psychosocial research

- Close liaison between R&D and clinical services – a clinical PI as well as research lead seems to be the best arrangement

- Culture which encourages grass roots engagement in and support for research; research leaders/ champions
Pre-requisites – universities

• Adequate funding/sources of funding available to conduct the planned research

• Good understanding of the demands of a clinical environment and ability to respond to this

• Full involvement of patients, members of the public and clinicians in all aspects of a project – fostered by clear communication
Conclusions

• Working on psychosocial studies is an on-going challenge – demanding close working, monitoring and revision of strategies over time

• The skills and knowledge of both clinical and research staff can be developed and extended through engagement in research

• The clinician/ academic role is ideal for the fostering of research across universities and trusts and ensuring implementation of research in practice
What have I missed?

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