Yorkshire and the Humber Dementia Clinical Network

Dementia Research Event
“Bridging the Gap to Evidence-based Dementia Care”
7th December 2016

• Twitter: @YHSCN_MHDN #yhdementia

www.england.nhs.uk
Welcome from host institution

Professor Murna Downs
University of Bradford
Housekeeping:

- Fire
- Toilet
- No phone
- Parking

#YHSCN_MH_DN
#yhdementia

www.england.nhs.uk
Welcome and Aims of the Day

Dr Kev Smith
Deputy Director, Healthcare, Public Health England, Yorkshire & the Humber
Morning agenda

9-9.40  Registration, networking, stalls and poster presentations

9.40   Welcome from host institution – Professor Murna Downs, University of Bradford

9.45   Welcome, aims of the day (Chair – Dr Kev Smith, Deputy Director, Healthcare, Public Health England, Yorkshire & the Humber)

9.55   Benefits of Dementia research (Dr Gregor Russell, Consultant Psychiatrist, Bradford District Care Trust)

10.15  Why I get involved in dementia research (Wendy Mitchell, person living with dementia)

10.30  How to ensure the family/carer’s perspective in research and its benefits (Ray Carver, Together in Dementia Everyday (TiDE))

10.45  Research: So What? (Paul Carder, Head of Research, 10 West Yorkshire CCGs)

11.05  MODEM and START: Research evidence into practice (Dr Kathryn Lord, Research Fellow, University of Bradford)

11.25  COFFEE

11.45  The role of the CLAHRC in supporting research into practice (Jo Cooke, Deputy Director and Capacity Lead, CLAHRC)

12.00  Sharing one trust’s approach to embedding a research culture – (Dr Nav Ahluwalia, Executive Medical Director & Director of Research, RDaSH)

12.15  Map of current research studies and introduction to afternoon session
Please tell us about your local Research or Innovation Project

<table>
<thead>
<tr>
<th>Main aim and intended outcomes</th>
<th>Which strand(s) of the dementia well pathway does this project relate to? Please tick:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Preventing Well □  Living Well □  Diagnosing Well □  Dying Well □  Supporting Well □</td>
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</tbody>
</table>

Other information

Key contact
Name
Email address
## NHS England Transformation Framework - The Well Pathway for Dementia

<table>
<thead>
<tr>
<th>Preventing Well</th>
<th>Diagnosing Well</th>
<th>Supporting Well</th>
<th>Living Well</th>
<th>Dying Well</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Risk of people developing dementia is minimised</strong></td>
<td><strong>Timely diagnosis, integrated care plan, and review within first year</strong></td>
<td><strong>Access to safe high quality health &amp; social care for people with dementia and carers</strong></td>
<td><strong>People with dementia can live normally in safe and accepting communities</strong></td>
<td><strong>People living with dementia die with dignity in the place of their choosing</strong></td>
</tr>
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<td>&quot;I am able to make decisions and know what to do to help myself and who else can help&quot;</td>
<td>&quot;I get treatment and support, which are best for my dementia and my life&quot;</td>
<td>&quot;I feel included as part of society&quot;</td>
<td>&quot;I can expect a good death&quot;</td>
<td></td>
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</tbody>
</table>

### Standards:

- Prevention^{(1)}
- Risk Reduction^{(6)}

### Standards:

- Diagnosis^{(1)(6)}
- Memory Assessment^{(1)(2)}
- Concerns Discussed^{(3)}
- Investigation^{(4)}
- Provide Information^{(4)}
- Care Plan^{(2)}

- Choice^{(2)(3)(4)}
- BPSD^{(6)(2)}
- Liaison^{(2)}
- Advocates^{(3)}
- Housing^{(3)}
- Hospital Treatments^{(4)}
- Technology^{(5)}
- Health & Social Services^{(5)}

- Integrated Services^{(1)(3)(5)}
- Supporting Carers^{(2)(4)(6)}
- Carers Respite^{(2)}
- Co-ordinated Care^{(1)(5)}
- Promote independence^{(1)(4)}
- Relationships^{(3)}
- Leisure^{(3)}
- Safe Communities^{(9)(5)}

- Palliative care and pain^{(1)(2)}
- End of Life^{(4)}
- Preferred Place of Death^{(5)}

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Mind the Gaps: the pathway to better dementia research

Dr Gregor Russell

Consultant Old Age Psychiatrist, BDCFT
Honorary Senior Lecturer, University of Manchester
NIHR CRN Dementia Lead West Yorkshire
The Problem

• What do we want?
• Responsive person-centred assessment, treatment and support for people with dementia across all stages of the condition- and support for their carers- all supported by high quality evidence of effectiveness.

• When do we want it?
• Now, ideally…

• What have we got?
• A patchy picture, with gaps between where we are and where we want to be in many areas.
The Problem

- Clinicians
- Service managers
- Commissioners
- Academics
- Industry
- NIHR
- Funding bodies
- 3rd sector
- Local authorities
- And of course- People with dementia and their carers
The Problem

- Determining a coherent research agenda
- What research is most important?
- What research gets funded- £90 million in 2012, “a further £300m of government funding by 2020”
- Who decides? How do they know?
- steps taken- peer review, patient input to proposals and grant applications, NIHR sets agenda for what is of national importance
The problem

- But gaps remain:
  1. The ‘gap’ between research being published and a resulting change in practice
  2. The ‘gap’ between how topics for proposed research studies are developed and the actual need for knowledge at the front-line
  3. The ‘gap’ in commissioned research for some strands of the Dementia Well Pathway
Gaps and how to bridge them
Gaps and how to bridge them

1/ Why doesn’t research change practice?

i) Mismatch with real world situation

Cognitive stimulation therapy in dementia

“People with mild-to-moderate dementia of all types should be given the opportunity to participate in a structured group cognitive stimulation programme”- NICE CG42
Why doesn’t research change practice?

• Around 14 sessions, trained staff, maintenance treatment- 1750 referrals per year to BDCFT memory services

• Patchy delivery of CST nationally- resources and numbers of trained staff available

• So interventions being evaluated should be scalable given likely resource constraints in clinical practice
Why doesn’t research change practice?

• ii) problems getting the word out
• START, STrAtegies for RelaTives-
  manualised 8 session psychoeducation
  programme for relatives of people with
  dementia, BMJ 2013
• Delivered by psychology graduates
• Supported by economic evaluation
• Not aware of any Y&H services offering this
• ? How many commissioners aware
Gaps and how to bridge them

- 2/ How do study topics get chosen and what do clinicians actually want evidence about?
- NIHR: “We work with a range of partners, including patients and the public, researchers, the Government, Health Authorities, charities and the James Lind Alliance (JLA) in identifying research priorities based on what matters to both patients and clinicians”
What do clinicians want?

- Priorities from canvassing senior colleagues:
  - 1/ better tools for early diagnosis, especially in patients with MCI
  - 2/ disease-modifying drugs for Alzheimer’s disease
  - 3/ post-diagnostic psychosocial interventions
  - 4/ models for intensive community support services that keep people out of hospital
  - 5/ nutritional issues in dementia
  - 6/ complimentary therapies
What do clinicians want?

• Looking at NIHR portfolio, system seems to be working reasonably well…

• 4-mountains test, MODEM, Journey into dementia, FINCH, caregiver hope, (and liaison service evaluation, culture-fair cognitive testing)

• But how to reflect local concerns and variations in national agenda?
Gaps and how to bridge them

• 3/ We may be diagnosing well, but are we dying well…?
• Not all strands of the pathway are equally represented
• Locally: 3 ‘diagnosing well’, 3 ‘supporting well’, 1 ‘living well’
• But clear gap in research into hospital care, end of life care
# NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

## Preventing Well
- Risk of people developing dementia is minimised

## Diagnosing Well
- "I was given information about reducing my personal risk of getting dementia"
  - "I was diagnosed in a timely way"
  - "I am able to make decisions and know what to do to help myself and who else can help"

## Supporting Well
- Access to safe high quality health & social care for people with dementia and carers
  - "I am treated with dignity & respect"
  - "I get treatment and support, which are best for my dementia and my life"

## Living Well
- People with dementia can live normally in safe and accepting communities
  - "Those around me and looking after me are supported"
  - "I feel included as part of society"

## Dying Well
- People living with dementia die with dignity in the place of their choosing
  - "I am confident my end of life wishes will be respected"
  - "I can expect a good death"

### Standards:
- **Prevention**: (1) Risk Reduction (5)
- **Diagnosis**: (1)(6)
- **Memory Assessment**: (1)(2)
- **Concerns Discussed**: (3)
- **Investigation**: (4)
- **Provide Information**: (4)
- **Care Plan**: (2)
- **Choice**: (2)(3)(4)
- **BPSD**: (6)(2)
- **Liaison**: (2)
- **Advocates**: (3)
- **Housing**: (5)
- **Hospital Treatments**: (4)
- **Technology**: (5)
- **Health & Social Services**: (6)
- **Integrated Services**: (1)(3)(5)
- **Supporting Carers**: (2)(4)(5)
- **Carers Respite**: (2)
- **Co-ordinated Care**: (1)(5)
- **Promote independence**: (1)(4)
- **Relationships**: (3)
- **Leisure**: (3)
- **Safe Communities**: (3)(5)
- **Palliative care and pain**: (1)(2)
- **End of Life**: (4)
- **Preferred Place of Death**: (6)

### Commissioning Guidance:
- Develop commissioning guidance based on NICE guidelines, standards and evidence-based best-practice.
- Agree minimum standard service specifications, set business plans, mandate and resources.
- Work with ADASS, PHE & other ALBs on co-commissioning strategies to provide an integrated service.

### Measurement:
- Develop Quality, Access and Prevention metrics to form the basis of the CCG scorecard.
- Identify data sources and agree with HSCIC, et al on the extraction processes.
- Set ‘profiled’ ambitions for each metric, to form the basis of the transformation plan.

### Transformation, Research, Innovation, Technology, Patient Engagement and Best-Practice:
- Transformation: using CCG scorecard to set & achieve a national standard for Dementia services.
- Intervention: Intensive Support Team to provide ‘deep-dive’ support and assistance for CCGs that fall short.
- Innovation: Intel from Research, Patient involvement, best-practice and technology to influence change.

References:
1. NICE Guideline
2. NICE Quality Standard 2010
3. NICE Quality Standard 2013
4. NICE Pathway
5. Organisation for Economic Co-operation and Development (OECD) Dementia Pathway
6. BPSD – Behavioural and Psychological Symptoms of dementia
Trouble with trolls…

- Or, what gets in the way of successfully crossing the bridges
- Knowledge of developments
- Cross agency engagement (today!!)
- Engagement of staff in clinical organisations (…my role as CRN dementia lead)
- Resources- ‘ETCs’ (good support locally)
Trouble with trolls

• Stuck with what’s coming down the NIHR pipeline vs developing local innovation capacity to set own agenda

• Involving patients and the public more generally (Join Dementia research publicity but scope for more)
Conclusion: No bridge too far
Conclusion: No bridge too far

- Dementia research on the threshold of a potential ‘golden age’
- National initiatives - the Dementia Research Institute, Dementias Platform UK, Dementia Discovery Fund
- The gap will be bridged
- Essential we have the local collaborations and structures to contribute for our population
Wendy Mitchell

Feel free to read my blog -
www.whichmeamitoday.wordpress.com

Or follow me on Twitter @WendyPMitchell
How to ensure the family/carer’s perspective in research and its benefits

Ray Carver, Carer

tide – together in dementia everyday ‘the voice, friend and future of all dementia carers’
Twenty years of caring for a husband with fronto-temporal dementia has taken a huge toll on my well being, my confidence, my interest in life and my own future. Being part of and actively involved in tide and it’s predecessor The Carers’ Call to Action has aided my recovery to believe in myself again in that I am not alone in my feelings, that I have something useful to contribute, and that I am entitled to seek to be happy again.
tide – together in dementia everyday

• Was created by carers for carers in April 2015 as a legacy from the Dementia Action Alliance’s Carers’ Call to Action campaign.

• Hosted by Life Story Network CIC, tide is an independent national involvement network for carers and former carers of people with dementia. Using lived experience, the network enables a diverse range of carers to have a powerful collective voice to bring them together under a common cause, building a social movement with the power to influence regional, national and international policy, aid research and influence the way in which local services are commissioned and provided, whilst raising awareness of carers’ unique needs and rights.

• The need for tide is recognised and supported by the Department of Health.
tide – together in dementia everyday
‘the voice, friend and future of all dementia carers’

Contact details

Web: www.tide.uk.net
Telephone: 0151 237 2669
Follow us on Twitter: @tide_carers

Please visit our stand and join us. You can sign up to us at www.tide.uk.net
Research: So What?

Paul Carder
Head of Research, 10 West Yorkshire CCG’s
Research:

So What?
Research: So What?

Otto Frederick Rohwedder
So What is Knowledge Transfer?

Knowledge transfer is the transfer of tangible and intellectual property, expertise, learning and skills between academia and the non-academic community, application in practice of knowledge gained from the research. This can be via publications, collaborations, training and/or events.
So What would help - A common language?
So What are the NHS’s Responsibilities?

**NHS Constitution**

‘…commitment to innovation and to the promotion, conduct and use of research to improve current and future health and care of the population’

**NHS Mandate**

‘duty to promote research and innovation – the invention, diffusion and adoption of good practice’

‘…to improve patient outcomes, but also to contribute to economic growth’
So What does the NHS look like?
So What might be the place to start?

Who are you trying to influence?

The Clinicians or The Commissioning Managers or both
So What are the current routes for enabling research into practice with Clinicians?

- Printed educational materials
- Educational meetings
- Educational outreach
- Local opinion leaders
- Audit and feedback
- IT solutions
- Contracting Solutions
So What are the plans that Commissioners are working to?

- STP – Sustainability and Transformation Plan (all NHS and social care)
- QIPP – Quality, Innovation, Productivity and Prevention (all NHS)
- CIP – Cost Improvement Programme (Providers)
- IAF – Improvement and Assessment Framework (Commissioners)
- NHS Outcomes Framework (all NHS)
- Public Health Outcomes Framework (public health and a bit of social care)
- 5YFV
- Plan for Growth
- Innovation Health and Wealth

All intended to be carried out using Evidence Based Commissioning
So What would Support Evidence Based Commissioning (EBC) & appeal to a commissioner?

• The Clinical CASE – Care and Quality Gap

• The Patient CASE – Health and Wellbeing Gap

• The Systems CASE – Finance and Efficiency Gap

• Otherwise SO WHAT?
So What is the Care and Quality Gap?

NHS Outcomes Framework;

Domain 1- Preventing people from dying prematurely

Domain 2 – Enhancing quality of life for people with long-term conditions

Domain 3 – Helping people to recover from episodes of ill health or following injury

Domain 4 – Ensuring that people have a positive experience of care

Domain 5 - Treating and caring for people in a safe environment and protecting them from avoidable harm

So What is the Care and Quality Gap?

CCG Improvement and Assessment Framework;

- Personalisation and Choice
- Health inequalities
- Clinical priority: Diabetes
- Child obesity
- Smoking
- Falls
- Anti-microbial resistance
- Carers

- Urgent and emergency care
- Primary medical care
- NHS Continuing Healthcare
- Elective access
- 7 day service
- Care ratings
- Clinical priorities:
  - Maternity
  - Dementia, Cancer,
  - Learning disabilities,
  - Mental health

- Quality of Leadership
- Workforce engagement
- CCGs’ local relationships
- Probity and corporate governance
- Sustainability and transformation plan

- Estates strategy
- Allocative efficiency
- New models of care
- Financial sustainability
- Paper-free at the point of care

So what is the Health and Well Being Gap?

- Improving outcomes and reducing inequalities;
- An upgrade to prevention and early intervention – shifting and refocusing resource;
- Adopting of new approaches, including an asset based approach which includes all sectors of the community;
- Linking health services to local community groups and the VCS;
- Increasing the use of technology to support delivery of services;
- Addressing the Care Act priorities including personalisation and information provision. E.g. people and patient-based based research
So what is the Finance and Efficiency gap?

- Demographic change
- A changing burden of disease as the number and life expectancy of people with one or more long-term condition increases.
- The local effect of national economic constraints in areas which impact on health service use
- Patients and the public expectations for the standards of care that they receive
- Increasing cost of providing services as the NHS now provides a more extensive and sophisticated range of treatments and procedures e.g. new drugs, technologies and therapies.
Thank you for listening

Any Questions?
MODEM and START: Research evidence into practice

Dr Kathryn Lord
School of Dementia Studies
Overview

• MODEM
  – What is it?
  – How can you use it?

• START
  – The evidence
Policy priority in England
What do we know?

Promising drug expected to become the first to slow down dementia found not work in the latest trial

- Scientists expected solanezumab to be the first drug to slow dementia
- Previous trials suggested it stopped toxic plaques forming in the brain
- But US pharma giant Eli Lilly and Company reported it showed no benefits
- It said it was now abandoning plans to apply for a licence for the drug

By BEN SPENCER MEDICAL CORRESPONDENT FOR THE DAILY MAIL

Internet of things set to change the face of dementia care

From digital assistants to ‘smart’ medicine bottles, a new wave of connected devices could help people live independently for longer

Dementia now leading cause of death

14 November 2016 | Health

There are many different types of dementia. Alzheimer’s is the most common form.

Dementia, including Alzheimer’s disease, has overtaken heart disease as the leading cause of death in England and Wales, latest figures reveal.

Dementia game 'shows lifelong navigational decline'

By James Gallagher
A health and science reporter, BBC News website
17 November 2016 | Health

The video game that's actually dementia research.

Revealed, how carbs can help you fight off dementia and keep your brain healthy

- Ageing expert Professor Preston Estep reveals what you should be eating
- He says low iron and glycemic index refined carbs can halt mental decline
- Common varieties of rice and pasta are better for the body than most
- Eating whole wheat products free of enriched iron might also help, he claims
Increased demand, fewer resources

What interventions should we be using?
MODEM: Modelling outcome and cost impacts of interventions for dementia

- Led by Professor Martin Knapp and colleagues at London School of Economics

- Newcastle University, University of Southampton, University of Sussex and the International Longevity Centre UK

- Funded by ESRC/NIHR Dementia Initiative
MODEM

http://www.modem–dementia.org.uk/

Launched in 2014

Dementia Evidence Toolkit

• Searchable database with over 1433 research studies on interventions for people living with dementia and their carers

Evidence Summaries

• Summaries of research findings for some of the main care and treatment interventions
The Evidence Table Key

Does it work?

✓ Worked well
✓= Worked well in some studies and made no difference in others
✓=× Mixed results it worked well in some studies, made no
difference in others and some found negative impacts
= Made no difference
=× Made no difference in some studies and others found negative
impacts
× Negative impact

Is it cost effective?

✓ It was cost effective
✓× It was found to be cost effective in some studies and not in
others
× It was not cost effective

What is the strength of evidence?
This rating will depend on a range of factors such as the type of
research for example if it was a Randomised Controlled Trial (RCT)
and the number of people who participated in the study.

/// High Quality
/// Moderate quality
Evidence Toolkit and Summaries

http://toolkit.modem-dementia.org.uk/

START: Strategies for Relatives

Professor Livingston and colleagues
Family carers in the UK

- 70–80% of people with dementia are cared for at home by a relative or friend

- 40% of carers of people with dementia have depression or anxiety

- Psychological symptoms in family carers predicts breakdown of care, institutionalisation and abuse
Psychological support for carers

• Psychosocial interventions for family carers are recommend as a key dementia care component (NICE / MSNAP).

• Prime ministers challenge on dementia 2020.

However.... Limited resources available in practice
START: STrAtegies for RelaTives

• Livingston & colleagues at UCL

• First RCT in the UK to test a manual based therapy for family carers of people with dementia

• Delivered one-to-one by psychology graduates

http://www.ucl.ac.uk/psychiatry/start
START intervention – 8 sessions

- Coping with caring
- Reasons for behaviour
- Making a behaviour plan
- Behaviour strategies and unhelpful thoughts
- Communication styles
- Planning for the future
- Introduction to pleasant events and your mood
- Using your skills in the future
START Results: Clinically effective

- Carers receiving START did better than controls at both the 8 months and two year follow-ups.

- After two years, carers in the control group were seven times more likely to be depressed than those who had received START.

- Quality of life was higher for carers receiving START than the control group.
START Results: Cost effective

- Costs were slightly higher for the START group because of the cost of the intervention.
- **START cost £232 per carer.**

- Carer costs over 2 years were £170 higher in the START group.
- Patient’s costs were £1368 lower in the START group.
Carer feedback

“NHS services gave a lot of information at diagnosis; too much negative info at once. I felt START was more supportive and gave smaller bits at a time”

“Sometimes I sit and go through my orange folder and there is a peace and understanding that someone is there with me”

“I now feel I have all the tools before she gets worse”

“What was an added bonus was that it centered on me rather than my husband. Previously all attention and energy had been focused on them”

“I felt it’s OK to be angry, upset, made to feel less guilty”
First study of family carers evaluating a structured psychological intervention delivered by psychology graduates.

Carer symptoms of anxiety and depression reduced after START, and remained lower after two years.

Rates of clinical depression increased in the control group and decreased in the START group and carer quality of life improved.

It is cost effective.

However.....
How to we make START available in practice?

July 2014 – Alzheimer’s Society Dissemination Grant

Research team support / Website

'Train the trainers'

6 month evaluation

12 month evaluation

Qualitative interviews
Train the Trainers

- Regional 3 hour training session for qualified clinical psychologists and dementia nurses.
- Introduce START and how to train and supervise others in delivering the intervention.
- Consider how to begin setting up START locally.
- Attending the training, the manuals, CD’s and all materials are provided free of charge.
Progress to date

October ‘14 – September ‘15

Locations:
- London x 2
- York
- Birmingham x 2
- Port Talbot
- Doncaster
- Edinburgh
- Cambridge
- Leicester
- Teeside
Implementation feedback

• Clinical Psychologists have implemented START in some areas. Facilitated by:
  – Existing skills to deliver this type of intervention
  – Buy-in from colleagues
  – Staff resources
  – Research team support
Barriers to implementation

• Admiral Nurses were not supervising anyone to deliver
  START
    – Not a part of their role / service structure
• Carer support not a service priority
• Lack of staff resource
START on MODEM

http://toolkit.modem-dementia.org.uk/evidence-summaries/
Conclusions

• MODEM can be used to compare evidence
• Important to consider the ‘quality’ of evidence when commissioning
• Need more funding and support to implement research into practice
Resources

http://www.modem-dementia.org.uk/

http://toolkit.modem-dementia.org.uk/

http://www.ucl.ac.uk/psychiatry/start
Time for a break?

20 minutes only please!
The role of CLAHRC YH in supporting research into practice

Professor Jo Cooke
Deputy Director
Capacity Lead
CLAHRC Yorkshire and Humber
Three pillars

• Applied research

• Research/ Knowledge implementation and actionable dissemination

• Building Capacity

All three pillars support getting research into practice
Making links and connections

THE
POWER
Of Connections
Our Partners

• Partners are organisations that contribute to ‘match’ funding

• White Rose Universities
  – Sheffield
  – Leeds
  – York

• Other academic
  – Sheffield Hallam
  – University of Bradford

• NHS partners
• 20 hospital, community trust
• CCG
• Local Authorities
• Charities
• Industry
• other
Themes that are most relevant

- Translating Knowledge into Action collaborating with Lab4Living
- Primary care based management of frailty
- TaCT theme
Projects and collaborating with others: co-production in research
Collaborating with others

- Joint work with EoE for grant capture
- Undertaking a scoping of academic grey literature to establish what is known about services for people living with Young Onset Dementia
- Care pathways for individuals diagnosed with Young Onset Dementia

Jane McKeown
j.mckeown@sheffield.ac.uk
CARE 75+ cohort

- Trials within cohort design
- Plan to recruit 1,000 people- ongoing
- Portfolio status
- Good for accessing vulnerable people. Some will have dementia

- Act as a recruitment site
- Use the Cohort in your own studies
Developing an person centred eye clinic for people with dementia

- Project was instigated by SHINDIG
- Working with designers to develop an eye clinic for people with Dementia who also have diabetes

Sheffield Dementia Involvement Group (SHINDIG)
Methods of engagement

- Photography in care homes: participatory visual methods as a vehicle through which to understand the experiences of people living in care homes

- Role of critical artefacts as a method of engagement
Actionable tools for dissemination
Primary Care based management of frailty in older people

- Electronic Frailty index (eFI)
- Embedded in SystmOne and EMISweb covering approximately 90% of the UK population
- 36 factors which have been constructed using around 2,000 primary care clinical codes (Read codes)
- Level of frailty can be identified
- Dementia with other comorbidities= Key factor
Primary care electronic Frailty Index (eFI): survival plots (n=227,648; >65y)

Proportion alive

Supported self-management
Care & Support Planning
Case Management/EoL care

Fit
Mild frailty
Moderate frailty
Severe frailty
Development of products in partnership with people with dementia

The Power of Sheffield Journeys

Development of an interactive resource in partnership with people with dementia to enable individuals who are at an early point of experiencing memory loss to have the opportunity to ‘rehearse’ their journeys using an interactive web platform:

http://www.skills4health.co.uk/trams/journey.html

‘travel their favorite journeys.

Currently developing ‘pop-up’ booths that can enable people in hospital and care homes to
Voice of dementia

The Voice of Dementia

www.clahrc-yh.nihr.ac.uk  CLAHRC Yorkshire and Humber
Capacity development

‘a process of individual and institution development which leads to higher skills and a greater ability to perform useful research’.
Look out on website

- Secondment opportunities
- Internships
- Support for fellowship applications
Acknowledgements

With acknowledgements to:

Key contacts

Deputy Director
Capacity Development Lead
Jo Cooke
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0114 226 5518

www.clahrc-yh.nihr.ac.uk
Twitter @clahrcyh
Linkedin CLAHRC Yorkshire and Humber
http://clahrcyh.wordpress.com

The NIHR CLAHRC Yorkshire and Humber is a partnership between 31 organisations including NHS, Higher Education, Local Authorities, Charities, Industry and the Regional Innovation Hub.
“Sharing one Trust’s approach to embedding a research culture”

Nav Ahluwalia
Executive Medical Director
Director of Research
RDaSH
5 things we have done

1. People who can deliver
2. Board support
3. ‘Demedicalise’ research image
4. All parts of your organisation must be represented.
5. Go outside
# RDaSH Availability of Principal Investigators

<table>
<thead>
<tr>
<th>Profession/Role</th>
<th>Number 2013</th>
<th>Number 2014</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lay Researchers</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Registered Nurses/Health Visitor</td>
<td>Not Known</td>
<td>13</td>
</tr>
<tr>
<td>Research Studies Officer</td>
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<td>Pharmacist</td>
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<td>2</td>
</tr>
<tr>
<td><strong>Psychiatrist (including trainees)</strong></td>
<td>Not Known</td>
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<tr>
<td>Occupational Therapist</td>
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<td>3</td>
</tr>
<tr>
<td>Psychologist (including trainees)</td>
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<tr>
<td>GP Trainee</td>
<td>Not known</td>
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</tr>
<tr>
<td>Other</td>
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RDaSH Stakeholder representation Good  
Clinical Practice Training April 2015

<table>
<thead>
<tr>
<th>Profession/Role</th>
<th>Number</th>
<th>Percentage</th>
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<tbody>
<tr>
<td>Lay Researchers</td>
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<td>Research Studies Officer</td>
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<td>12.5</td>
</tr>
<tr>
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<td>12.5</td>
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<tr>
<td><strong>Psychiatrist</strong></td>
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<td><strong>12.5</strong></td>
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<tr>
<td>Psychologist</td>
<td>1</td>
<td>6.25</td>
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<tr>
<td>Health &amp; Wellbeing Practitioner</td>
<td>1</td>
<td>6.25</td>
</tr>
<tr>
<td><strong>GP Trainee</strong></td>
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<td><strong>6.25</strong></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td>16</td>
<td><strong>100</strong></td>
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</table>
5 things we have done

1. Get people who can deliver
2. Get Board support
3. ‘Demedicalise’ research image
4. All parts of your organisation must be represented.
5. Go outside
Introduction to afternoon session

Chris Rhymes, Lead Research Nurse, NIHR Clinical Research Network
Penny Kirk, Quality Improvement Manager, Yorkshire & Humber Clinical Networks
Please tell us about your local Research or Innovation Project

<table>
<thead>
<tr>
<th>Project title</th>
</tr>
</thead>
</table>

**Main aim and intended outcomes**

| Which strand(s) of the dementia well pathway does this project relate to? Please tick: |
| Preventing Well | Living Well |
| Diagnosing Well | Dying Well |
| Supporting Well | |

**Other information**

**Key contact**

Name  
Email address
### Workshop 1A: Supporting Well

**Chair:** Dr Nav Ahluwalia

<table>
<thead>
<tr>
<th>Time</th>
<th>Researchers &amp; Universities</th>
<th>Study topic &amp; Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.15</td>
<td>Professor Jan Oyebode, Bradford</td>
<td>RHAPSODY – improving support for carers of younger ppl with dementia</td>
</tr>
<tr>
<td>1.30</td>
<td>Professor Gillian Parker, York</td>
<td>Life Stories Research, Care Homes</td>
</tr>
<tr>
<td>1.45</td>
<td>Dr Penny Wright, Leeds &amp; Professor Jan Oyebode, Bradford</td>
<td>DECIDE - outcomes of relevance to carers</td>
</tr>
<tr>
<td>2.00</td>
<td>Discussion session</td>
<td></td>
</tr>
</tbody>
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### Workshop 1B: Caring for People living with Advanced Dementia and Dying Well

**Chair:** Professor Claire Surr

<table>
<thead>
<tr>
<th>Time</th>
<th>Researchers &amp; Universities</th>
<th>Study topic &amp; Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.15</td>
<td>Dr Donna Maria Coleston-Shields, Nottingham</td>
<td>Evaluating best practice in Dementia Crisis Teams (AQUEDUCT)</td>
</tr>
<tr>
<td>1.30</td>
<td>Professor Margaret Holloway, Hull</td>
<td>The Continuing Self: Dementia and the Spiritual Journey</td>
</tr>
<tr>
<td>1.45</td>
<td>Professor Esme Moniz-Cook, Hull</td>
<td>Challenge Demcare study</td>
</tr>
<tr>
<td>2.00</td>
<td>Discussion session</td>
<td></td>
</tr>
</tbody>
</table>

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In here

‘A’ for Auditorium

Upstairs
## Workshop 2

### Workshop 2A: Diagnosing Well and Living Well (Chair: Dr Sara Humphrey)

<table>
<thead>
<tr>
<th>Time</th>
<th>Researchers &amp; Universities</th>
<th>Study topic &amp; Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.30</td>
<td>Dr Dan Blackburn, Sheffield</td>
<td>Conversation analysis in dementia screening &amp; diagnosis</td>
</tr>
<tr>
<td>2.45</td>
<td>Dr Sarah Kate Smith, Sheffield</td>
<td>IN LIFE – ICT solutions, Own home</td>
</tr>
<tr>
<td>3.00</td>
<td>Professor Gail Mountain, Bradford</td>
<td>Journeying Through Dementia</td>
</tr>
<tr>
<td>3.15</td>
<td>Discussion session</td>
<td></td>
</tr>
</tbody>
</table>

### Workshop 2B: Whole Pathway (Chair: Dr Kathryn Lord)

<table>
<thead>
<tr>
<th>Time</th>
<th>Researchers &amp; Universities</th>
<th>Study topic &amp; Care Setting</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.30</td>
<td>Dr Sahdia Parveen &amp; Professor Jan Oyebode, Bradford</td>
<td>Improving access to services for people from BAME communities</td>
</tr>
<tr>
<td>2.45</td>
<td>Dr Kate Gridley, York</td>
<td>Evaluating support for carers of people with dementia, Own home</td>
</tr>
<tr>
<td>3.00</td>
<td>Professor Claire Surr, Leeds Beckett</td>
<td>What Works Study (education methods)</td>
</tr>
<tr>
<td>3.15</td>
<td>Discussion session</td>
<td></td>
</tr>
</tbody>
</table>
Discussion sessions

Issues for consideration:
• Public perceptions of research
• Recruiting sites
• Patient pathways
• Opportunities to simplify the study
• Commissioning for evidence based care
• Gaps in commissioned research

Feedback from chair (3 key points) to the main group
Time for some lunch?

Workshop sessions will start at 1:15pm

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