

# FINCH Study – Summary of discussion

Thursday 4th September 2015 10.30am – 16.00pm

**Attendees:-** Claire Goodman (CG), (chair), Frances Bunn (FB), Jo Rycroft-Malone (JRM), Bridget Russell (BRu), Karen Cummings (KC), Brenda Roe (BRo), Rowan Harwood (RH), Vari Drennan (VMD), Mandy Fader (MF), Danielle Harari (DH), Christine Norton (CN), Lindsey Parker (LP)

## *Appointment of Research Fellow CG*

The position for the Research Fellow post was advertised twice. On the first occasion there were no applicants and BRu applied on the second occasion and has been appointed a Research Assistant on a part-time basis until December 2014. The HTA have been informed and have agreed with this arrangement. The post will be reviewed again in December. CG welcomed BRu to the team.

## *Contract and research agreements CG*

CG advised that UoH contracts department were planning to use the Brunswick Agreement for the sub-contacts. It was highlighted that this may be an issue for NHS contracts and if institutions were not already signed up to accept Brunswick Agreements. **AP – LP to confirm procedure with UoH contracts dept**

CN requires a copy of the protocol in the HTA template (without financial information). **Action – LP to send**

## *Protocol including changes post submission and project milestones (paper A & B) CG*

Papers A & B, protocol and Gantt chart – CG asked if there were any points of clarification and confirmed the intended date was the 1<sup>st</sup> September 2014. BRu has developed a linear Gantt chart which was also tabled.

It was confirmed that HTA had rejected the additional intervention work of @£20k and that this should be discussed with the Steering Committee. **Action- LP to add to Steering Committee meeting agenda**

## *Overview of the assumptions of realist synthesis CG/JRM*

CG summarised the key principles of Realist Synthesis (RS) and the fact that this is a theoretically driven review that recognises there are multiple explanations/theories about what may or may not support the effective management of faecal incontinence (FI) for people with advanced dementia in care homes. Therefore, we should consider a range of sources that can inform further work on what works when, in what circumstances and with what outcomes. We will not be limited to studies that are only focused on FI. JRM explained that it starts with specific literature and then broadens out, setting up theories to look at evidence to test.

CN added that constipation and urinary incontinence must be included for meaningful outcomes for this generation. BRo questioned the definition of ‘advanced dementia’ and therefore if we would include dementia generally. DH commented that colloquially advanced dementia means resisting care, either passively or aggressively; the consensus was to include useful evidence from earlier stages. JRM advised that all types of evidence were equally as important, the challenges can be vast and that there would need to be a close record as we go along. CN added that it would be helpful to have a good example of a high quality review – **Action JRM to provide**

***Preliminary scoping of the literature, proposed approach and discussion of key theoretical sources/papers/databases a: - i***

CG asked the RMT to talk about the big ideas in their areas, favoured outcomes and impact.

***The physiological and clinical causes/associations of faecal and consequent morbidity in the oldest old – CN/DH***

CN - Main bowel causes are constipation, diarrhoea, laxatives, laxative induced diarrhoea and association. CN can send two 2 recent papers on urinary incontinence, neurological problems, polypharmacy, comorbidities, impaired activities in daily living.

The physical and social environment are recognised as being of central importance; i.e. the care home and staff. There is a huge variability between care homes, which is possibly not to do down to the residents and more to do with care environment and philosophy. **Action CN**

DH - Brocklehurst looked at case mix across a lot of care homes in the UK and there was a huge variation and it implied that the residents were not different but outcomes of care were. **Action retrieve Brocklehurst paper**

CN – outcomes are being measured very crudely at the moment, mainly on an individual's output rather than in terms of physical comfort, skin care, UTI's etc.

DH – staff confidence in their own knowledge and not always attitudes makes the difference – there is a lack of thinking about how to manage FI, an assumption that old people are incontinent leading to a lack of effort to improve the situation.

Possible to change things through education and by examining continence interventions, i.e. incontinence/link nurses or GP's with a special interest regularly monitoring and pushing forward good practice.

CN – the nursing focus group which she is working with in Norway have said that FI is not the problem it is constipation which is the issue. FI was often normalised and “treated” with pads. This could explain the difference in how care homes explain the prevalence of FI in care homes, i.e. if they are wearing pads then they are not faecally incontinence. CN highlighted that it appears to be constipation that leads to hospitalization.

Stroke, diabetes and Parkinson's, pre-existing medical conditions cannot be excluded as contributing factors.

RH – mindset in Norway good care/end care should be dignified empathic care because you can't do anything because there is nothing that works. Literature about stroke recovery shows that lack of ability to move and/or communicate leads to incontinence when the bladder itself is healthy.

DH – Probably 50% of FI in dementia is due to laxative over-use, also other drugs may interact with laxatives, e.g. SSRIs, iron supplements. Comorbidity of diabetes, Parkinson's etc. need to be considered as influences on Medication reviews in care homes should include these factors and interactions.

CN – bowel disease should not be missed – IBD, Cancer

RH – Polypharmacy – pharmaceutical conflicts & knowledge– what drugs do cause diarrhoea and conflicting clinical priorities.

CG – how does frailty fit – do we need to engage with the frailty literature as FI another marker for frailty?

DH – Using the frailty index to classify their frailty factors and not just classifying as frail or not frail could be useful.

MF – physiological aspects of offering mobility and toileting opportunities so that people could be continent.

MF to provide information for link to the latest international continence society review book for summary chapters. **Action MF**

DH - highlighted the importance of diet and literature around catheters and in-particular - STOP which is about nursing empowerment. **Action DH provide reference**

MF – Most people have both urinary and faecal incontinence therefore pads are the method used for containment. Devices are either anal plugs, which are not usually used for this group, drainage for diarrhoea in UTI situations or sealed bags for use in more critical care situations when people are unconscious.

The literature on dementia is predominately in care or nursing homes there is almost nothing in the community on managing with incontinence pads. Areas of interest are containment - which of the designs are best for double incontinence.

Study looked at what kinds of designs are easier for carers and patients to manage themselves - i.e. during the day pull up pants work well but not good for the night if the patient is not mobile. You would need a different design dependant on if you can stand or not stand. What we don't know is what is best but there are theories of what that might be but it comes down to the individual. **AP MF to provide relevant literature on this**

There is also the issue of the empowerment of nurses to perform necessary procedures e.g. the removal of a urinary catheter, without permission from a doctor.

JRM- what is the scope of improving faecal incontinence, it's about managing and containment?

CN containment must be included for very advanced dementia.

MF- faecal and urinary mix is the most aggressive skin environment and understanding how that works is crucial and managing incontinence well. How you clear up is not taught, care homes have adopted their own methods and it would be good to know what strategies work well.

RH - Managing and cleaning up might relate to an outcome.

VMD – The International Continence Society have a paradigm which is very clear; being continent independently through being continent dependently through to containment. It is important to realise that there are these different stages and it's not just about prevention of incontinence it is about outcomes.

**AP VMD to provide Contience Society reference/document**

BRo – We need to have an operational definition - incontinence glossary – a defining document; NICE document? ICS – International Continence Society's are possible definitions. NICE quality standards makes five statements. **AP Develop a glossary of continence relevant/related definitions for FI**

RH – JRM Talked about holding different things in our minds at the same time – you could put a structure outcome process but there is an important knowledge aspect within the structure, access to specialist services or to medical care, process in terms of how people manage/monitor bowels,

constipation avoidance etc. Outcome will be another area; we can talk in terms of cure rates, containment, dignity, distress, staff agenda. There will be lots of overlap.

CG – We're not going to have a 'managing definition' now, this is just for everyone's ideas and the deliverable from this meeting is that we have something defined for this project.

DH – pain and discomfort – pain killers either too many or not enough and skin discomfort becomes crucial, these are cost cutting themes.

CG - How do you define advanced dementia – is there anything particularly about advanced dementia that is extra?

VMD - From work done in primary care and people's homes – people with dementia often manage to maintain dependent continence in their own homes. The thing that often gets muddled in care homes around whether they are continent or incontinent is that there are a range of things or contexts which lead to a whole range of different toileting issues.

RH- Ultimately everyone with dementia will become incontinent by the last stages of the disease. Source documents: - Graham Stokes book and study observing patients toileting in care homes – commissioned by the RCP & BGS and evaluation team by the University of Kent. **AP RH provide reference to Graham Stokes book**

VMD –Need to keep in mind - every culture holds in disgust faecal matter in terms of what it brings, this goes back to Goffman and stigma and Mary Douglas' work on purity and danger also see– **Val Curtis London School of Hygiene**  
**[http://www.lshtm.ac.uk/newsevents/multimedia/video/2013/val\\_curtis\\_disgust.html](http://www.lshtm.ac.uk/newsevents/multimedia/video/2013/val_curtis_disgust.html). (Book: Don't Look, Don't Touch, the Science behind Revulsion, OUP, 2013)**

In a study involving people with earlier dementia talking about how it felt to be incontinent – it became clear that hiding activities or cleaning was not to contaminate others but rather because other people should not have to deal with your dirt – not just about shame and embarrassment.

MF-the thing that people with incontinence hate most after leakage is smell. **So smell as an outcome** in improving in terms of management.

FB - comorbidity in dementia study– nothing specific which crosses over with FI in dementia. There are issues around self-management and when carers take over the role – when managing crosses over.

RH- There is no set definition when dementia becomes advanced – the assumption is that a person would have lost the ability to communicate, become immobile, incontinent, have difficulties feeding – functional assessment scale.

Once you have advanced dementia you are approaching the end of life and have more than a 50% chance of dying within 6 months, need to think about a palliative care.

Kitwood philosophy of person centred care/ VIPS model.

Nothing contradictory between person-centred care and end-of-life care.

We have to challenge what is reasonable – mapping everything which could be relevant.

CG- Inter-professional working – responsibility for decisions differs there is emerging theory around care homes.

There are theories of how groups learn, associations with people, confidence, learning and teaching. In care homes there is the issue that it is the health-care professional or specialist i.e. in continence, who comes in to advise and how does that inter-professional relationship work? – Whose expertise is heard and where does the expertise sit?

Theories about how groups organise – is there something about the different configurations and outcomes.

DH - Scheduled medication issues and the GP has not seen the patient.

CG- Care home literature around who does what when.

BRo - Relationship with regulators.

DH- Continence doesn't feature in the CQC.

CN – Evidence of increased staff turnover – theory to test.

KC – Safeguarding is a huge issue in care homes and all carers work under that. Not just confidence also permission.

‘**Environment**’ keeps coming up – and toileting environment.

RH-‘World view’? What’s expected, what’s normal – people see catheters as a way around incontinence.

Lord Justice Munby speech, safeguarding as abuse. **AP RH provide link/reference**

JRM – world view issue is fundamental to culture. Implementation practical development, changing things from the ground up, implementation from the evidence, what does the evidence tell us, what should we be doing, how do we change things in accordance with evidence. The importance of context – physical context, social context, emotional context, culture. There are a number of big themes around context from discussion today.

Would in a specific way and then look how all these other literature can inform what we should be doing to improve things.

Utilise frameworks around implementation, e.g. the Paris framework, ICONS framework, FIRE study, possibly using normalisation process theory

CN – if you could have only **one marker to rate the quality of a care home**, for me it would be the rate of FI as it encompasses so much. A good care home will get the rate down to about 25%.

Education and training can be used as a quick fix but staff move on.

Change management principles – fluid staff which includes the visible leaders/managers. The care home manager is key.

CG – Outcome measures – Initially the RS will map every conceivable outcome which could relate to FI.

CG – In summary cost cutting themes: - environment, context, education, stigma, culture, implementation literature. **Action point for all** – to send reviews, papers and anything which has been referred to today to BRu to capture dominate ideas.

Strategies for managing FI – what’s being used?

Nothing is being ruled out at this time, dementia/advanced dementia – include all care homes and residential settings for evidence, as ‘care homes’ means different things in different countries.

Summary, map it out and then circulate big themes to stakeholders.

### ***Identification and invitation of stakeholders and workshop dates***

CG - 5 stakeholders groups identified - a list will be circulated for names to be added to – **Action BRu**

We need a social care representative, policy makers, CQC, Alan Rosenbach, NICE, quality standards.

UoH ethics will be gained for the focus groups.

Workshops dates for research team to discuss scoping results and what the stakeholders have said – date agreed as Friday 16<sup>th</sup> January 2 – 5.30pm. **Action point CN to book a meeting room.**

### ***Patient and Public involvement***

PPI – names for dementia/continence people, resident PPI through care homes, ACA **Action DH** to advise contact

## **Phase one: Defining the scope of the review: concept mining and theory development: briefing update**

### **Aims:**

- Develop programme theories or hypotheses about why FI management programmes for people with advanced dementia living in care homes work or do not work
- Provisional account of the impact of interventions by linking key areas of knowledge that inform how interventions are developed for this particular population

### **First scoping of the literature - process**

#### **Identification of relevant studies**

For the initial scoping search we began by focusing on papers relating to implementation in care homes, continence interventions in older people and person-centred care for people with dementia. We searched PubMed and the Cochrane Library. The search terms used in PubMed can be seen below. Electronic search results were downloaded into EndNote bibliographic software and, where possible, duplicates were deleted. Records were then screened by one reviewer (BR) and those identified as ‘yes’ or ‘possible’ were checked by a second reviewer (CG, FB).

Further searches were conducted through Google Scholar for National Institute of Health and Clinical Excellence (NICE) guidelines and similar, yielding 23 documents. Forward searches were carried out from the reference lists of key review documents identified through the first search, (Coggrave et al., 2014; Flanagan et al., 2012; Flanagan et al., 2013), producing another seventy one documents.

Electronic searches and literature from the RMT resulted in 1,862 records; of these 203 articles have not yet been acquired for assessment. Two further areas for scoping were identified that emerged from the stakeholder interviews: nutrition and hydration and facilitation interventions to support care home staff achieve change. A review of reviews in these two areas was undertaken.

Currently 1,383 documents have been screened (1,659 less 186 duplicates). An overview of the selection process can be seen in Figure 1.

**NB: This is the working document sent to the RMT and we are fully aware that the flowchart and numbers in the narrative do not tally. This was picked up at the meeting and addressed. However this is a record of what was sent to the team**