

Dear,

Thank you for your interest in our research.

Attached to this email is the official information sheet, which explains what we aim to investigate. It also highlights that anything you tell us is confidential and anonymous and that you can withdraw from the study at any time.

Another attachment is the consent form, please read this, if you are happy to participate, please email me an address so that I can post you a paper copy for you to sign and return to me in a prepaid envelope. Alternatively, a scanned signed copy can be emailed to me.

The third attachment is a summary of our findings to date, the summary is slides from a recent presentation. Without the spoken words they may not make complete sense but they hopefully give you a feel for the emergent findings.

Background factors

- a. Ongoing training with support from visiting clinicians to review care and provide feedback on care practices, to create a workforce that understands the problems of living with dementia and can identify and address continence related issues
- b. Timely nurse/physician led assessment of continence needs for people with dementia, with prompt appropriate treatment for any problems
- c. Using continence care techniques which take into account the physical and cognitive capacities of the person with dementia

Key factors

1. Using techniques which fit with the work flow of the carers in an organisational atmosphere which encourages carers to adapt to the needs of people with dementia
2. Establishing a common understanding that FI can be cured, reduced or managed with dignity for people with dementia

To summarise, the studies we've looked at and the interviews we've run with doctors, nurses, care workers and families suggest that if all three of the background factors are in place staff in care homes will have the knowledge and skills to give appropriate care, if the organisation's ethos allows them to adapt that care within reason, to provide what's best for a specific person in a particular situation (key factor 1) and while everyone within the organisation understands that FI is not inevitable or irreversible (key factor 2).

We'd like your comments on these findings do they ring true? Are there gaps? We'd also like to hear any insights which your experiences provide. The ideal way for us to gain your insights would be a phone conversation, then we can ask questions to clarify the points you make. We would ring you at a prearranged time which is convenient for you.

Thank you again for taking an interest in this research.



FINCH

Managing Faecal Incontinence in people with advanced dementia resident in Care Homes

Ethical approval No: HSK/SF/UH/00088

An invitation to family members and relatives of residents to take part in a telephone interview

Invitation

You are being invited to take part in the FINCH study which is looking the problems associated with faecal incontinence (FI) for people with dementia living in care homes and the possible solutions. We will look at what works well, for which people and in what situations. We will also look at what doesn't work and why.

As a family member or relative of someone with both dementia and FI we would like to invite you to participate in this research.

About the FINCH study

Older people in care homes have their everyday care and support needs met by care home staff; this includes assistance with visiting the toilet if necessary. We

would like to include your views about the problems and the best solutions for managing faecal incontinence for someone with dementia, so that distress to the person is minimised and health and dignity are maintained.

What will happen in the interview?

A member of the research team, probably Bridget Russell, will call you at a prearranged convenient time. The interviewer will check that you are still willing to take part and that the time is still convenient. You will be told about the information we have gained during this research project and asked to comment on it from your own experiences. You can choose not to answer questions without giving reason and we understand that you may not have comments to make on every point.



INVESTOR IN PEOPLE



FINCH is a collaboration between the Universities of Hertfordshire, Bangor, Southampton Edgehill, Kingston & St Georges University of London, St Mark's Hospital, Nottingham University Hospital and Guy's & Thomas NHS Trusts and The Orders of St John Care Trust. This study is funded by the NIHR Health Technology Assessment Programme (HTA)

Participant Information Sheet: Family Version 1. 04/11/2014

A charity exempt from registration under the Second Schedule to the Charities Act 1993

Confidentiality

Any information you provide to us will be treated with full confidentiality:

- Your information will not be passed on to anyone else outside the research team.
- Your information will be stored on a password protected computer which will be kept in a locked office when not being used by the lead researcher.

The information from the project will be used to inform a number of articles for publication in academic journals.

To ensure confidentiality where information is being used in publications, all information will be anonymised so that no-one who participated in the study can be identified.

With your permission the interview will be recorded, to help the researcher recall the full discussion, alternatively she will just take notes. The recording will be destroyed at the end of the study, and you will not be identified by name in any of the paperwork for this research.

Exceptions to confidentiality

Very rarely there is a risk that information about misconduct or safeguarding issues may be revealed. If this happens the researcher has an obligation to inform the relevant authorities. The researcher will discuss this with you before revealing the information and explain why it is necessary.

Typical questions we will ask you

- How would you define faecal incontinence?

- What helps your relative most?
- What hinders your relative most?

What if I do not understand the questions that are asked or find I do not want to discuss something in the focus group?

The researcher will explain the study and the discussion as fully as possible. However, you do not have to comment on anything that you would prefer not to.

Consent

It is up to you if you decide to join the study. If you agree to take part you will be asked to sign a consent form and post it back in a prepaid envelope.

We want you to feel fully informed before you give consent. This leaflet provides the most important information but if you need more, or would like something clarified please ask the researcher when you talk, or contact one of the project staff listed at the end of this information sheet.

What if there is a problem?

We don't anticipate any problems but if one arises, for example, if you have a concern about the way you have been dealt with, or about any aspect of this study you should ask to speak to Claire Goodman (lead researcher) on: [REDACTED]

If you are harmed by taking part in this research project there are no special compensation arrangements. If you are harmed due to someone's negligence then you may have grounds for a legal action for compensation against the University of Hertfordshire but you may have to pay for it. Should you require independent advice about making a complaint or seeking compensation you may wish to contact the Independent

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Complaints Advocacy Service (ICAS) (Tel: 0845 456 1082).

Who has reviewed the study?

Before they can go ahead, research projects are scrutinised by ethics committees whose job is to protect the interests of everyone who takes part.

This study has been reviewed by the University of Hertfordshire Health & Human Sciences Ethics Committee with Delegated Authority and has received a favourable judgement.

Who is funding the research?

This study is being funded by the National Institute for Health Research Health Technology Assessment Programme, (No. 13/75/01).

What do I do if I would like to take part?

You can ring or email **Bridget Russell** *directly* if you would like to more information.

THANK YOU.

Your contact is:

Bridget Russell, Research Assistant, University of Hertfordshire

Tel: [REDACTED]

Email Contact details: [REDACTED]

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FINCH:
*Managing Faecal Incontinence in people with
advanced dementia resident in Care Homes*

CONSENT FORM

Participant code _____ A1 _____

Ethical approval No: HSK/SF/UH/00088

Please tick box

I have received and understood the focus group information
leaflet for the FINCH study.

Focus group relatives information sheet V1. 04/11/2014

I have been able to ask questions about the study, and my
questions have been answered in a way that I understand
and I am satisfied with.

I understand that it is my choice whether I take part in the study.

I understand that I can stop taking part at any time and that
this will not affect my relative's care in any way.

I understand that the group discussion is confidential and agree
not to pass on any information shared in the group.

I understand that the researchers are obliged to break confidentiality
if they hear of malpractice or safeguarding issues.

I agree that an audio recording will be made of the focus group, and
understand that it will be destroyed at the end of the study.

I agree to take part in the FINCH study.

Participant name _____ (Print name)

Signed _____ Date _____

Researcher name _____

Signed _____ Date _____

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Participant Consent Form: Family Version 1. 04/11/2014

One copy for participant, one copy for researcher

DRAFT

DRAFT FINDINGS

NOT FOR PUBLICATION

Reducing and managing faecal incontinence (FI) in people with dementia who are resident in care homes: a realist synthesis

Aim (as funded): To explain the effectiveness of programmes that aim to improve faecal incontinence (FI) in people with advanced dementia

Reason for the Research

To look at care for people with faecal incontinence and dementia.

To ask 'what works, for whom, in what circumstances?'

Care Homes

- Approx 17,500 care homes in England
- Two thirds residents living with dementia, a third of whom have advanced dementia
- Prevalence of faecal incontinence highly variable in care homes = **quality** of care?

Continence as part of the context in caring for someone with dementia

Our initial definition of continence was:

“leakage of solid or liquid stool which is a social or hygienic problem” (Norton et al 2009)

We expanded this to include a definition that considers dementia

“The voiding of urine or faeces either following an unsuccessful effort, or with no apparent attempt to employ an acceptable facility (e.g. toilet, commode, urine bottle)” (Stokes 2013)

Stokes, talking specifically about dementia care, proposes a checklist of toileting difficulties where incontinence is one of nine influencing factors

Why does faecal incontinence happen?

There are many influences, here
are some of them...

Multiple possibilities

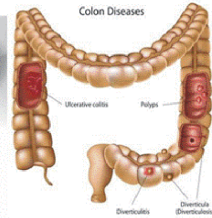


constipation

Communication



Assessment
knowing the
resident



University of
Hertfordshire

resident

Outcomes of interest

People with dementia and their families

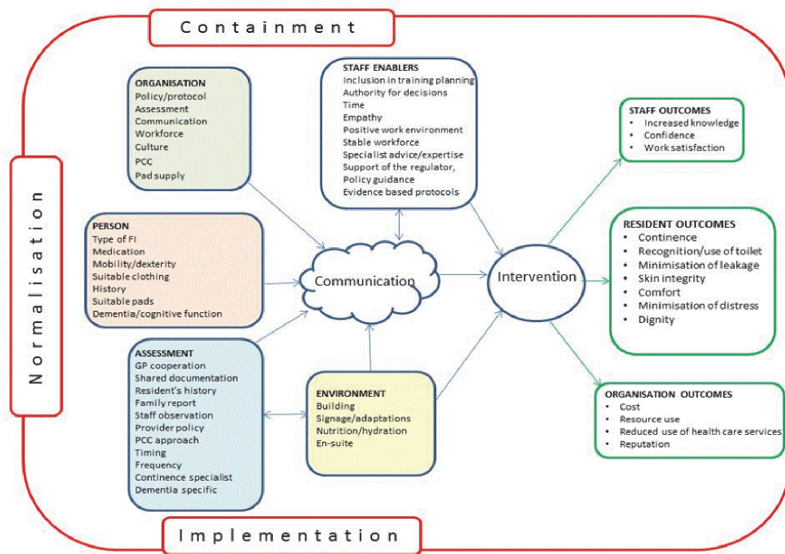
- Continence (assisted if necessary)
- Recognition and use of toilet
- Minimisation of leakage
- Skin integrity
- Comfort
- Less distress
- Maintaining dignity

Organisations

- Staff knowledge about continence care
- Staff attitudes to aging and dementia
- Staff confidence
- Work satisfaction

- Appropriate use of continence pads and laxatives (resource use)
- Cost
- Reduced use of healthcare services
- Reduced workforce turnover
- Reputation

Emergent findings from published research



Some theories about what is helpful

1. Fit with working practices and CH culture triggers 'doing the right thing'
2. Interventions that understand and incorporate how the cognitive and physical capacity of the resident affects their continence (personalised care)
3. Nurse or doctor led support, assessment and review will increase care staff confidence and reduce anxiety about liability when enacting care plans to reduce FI
4. Having a common understanding among staff of the potential for recovery, reduction and management of FI for people with dementia will trigger attempts to understand what is causing FI
5. Ongoing teaching, review and feedback for and with staff that involves care home staff (e.g. PDSA) will reinforce behaviour change in staff that means continence care is seen as a priority.
6. Staff that are confident to assess/recognise, manage and treat for constipation triggers a focus on all aspects related to bowel care

Evidence included

- 62 studies included
 - 39 continence specific
 - 18 offered transferable learning (e.g. interventions seeking practice change in care homes)
- Interviews and focus groups with, GPs, continence nurses, geriatric specialists, care home providers, managers and staff and relatives of care home residents with dementia

Silo thinking...

When Dementia is only seen as a risk factor



Twenty continence studies included people living with dementia, only 16 had an 'assessment' for dementia and only ONE considered impact of dementia on continence

Stating the obvious

Many instances of FI could be 'cured' or greatly reduced by integrating person centred care (PCC) with nurse/physician led continence assessment to address the underlying causes of FI (e.g. constipation or drugs for other conditions) AND ensuring that PCC and continence care together, is incorporated into the intimate and personal care work of frontline care staff

Most promising approaches are those that address...

- How direct care staff understand continence care *as* personal and intimate care and are enabled to incorporate it with their other responsibilities and care priorities
- The dementia specific challenges that can occur when toileting or using continence aids/pads



FINCH research team

- Claire Goodman, Frances Bunn, Bridget Russell, Marina Buswell University of Hertfordshire
- Christine Norton Kings College London
- Jo Rycroft-Malone Bangor University
- Danielle Harari Guy's and St Thomas' NHS Foundation Trust & Kings College London
- Vari Drennan St George's and Kingston University
- Brenda Roe, Edge Hill University
- Rowan Harwood University of Nottingham
- Mandy Fader University of Southampton
- Michelle Maden University of Liverpool
- Karen Cummings Order of St John Care Trust



Acknowledgement and Disclaimer

This project is supported by the National Institute Health Research (NIHR) HTA project 13/75/01 Managing Faecal Incontinence in people with advanced dementia resident in Care Homes, a realist synthesis of the evidence (FINCH study). It will be published in full in Health Technology Assessment (www.hta.ac.uk)

The views and opinions expressed are those of the authors and do not necessarily reflect those of the HTA programme, NIHR, NHS or the Department of Health.