

# Research in the hidden places- the challenges and opportunities for nurses

Vari Drennan,  
Professor of Health Care & Policy Research,  
Faculty of Health , Social Care and Education  
Kingston University & St. George's University of London,  
London, England.

# Plenary objectives

## Provoke ideas

**Catch your interest**

**Give you something to discuss with others**

**Hear something new**

**Enjoy the visuals**

**Respond to disagree or agree**

**Entertain**

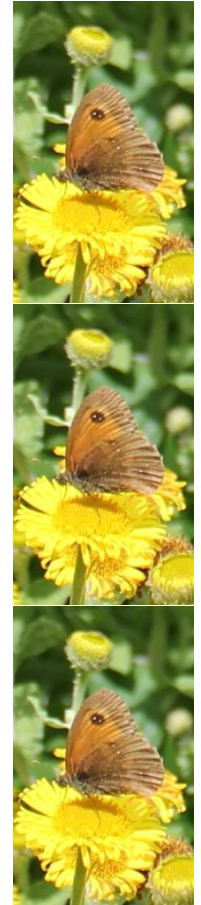
# Outline

- Trends in health care globally
- What are hidden places ? Hidden to who ?
- Why might it be important to research in such places, particularly for nurses ?
- Illustrate the above through a programme of research concerned with dementia and incontinence,
- Invite you to respond.



# Context setting

- **Changing demography & burden of disease** in most countries – populations migrating , living longer and with more chronic diseases,
- **Increased costs** of medical technology,
- **Financial constraints** for health services (irrespective of type of funding system – tax/insurance ),
- **Paradigm shifts in health care** to prevention, to self management, to primary health services , to ambulatory services, to minimising time in expensive (and risky) hospital settings.



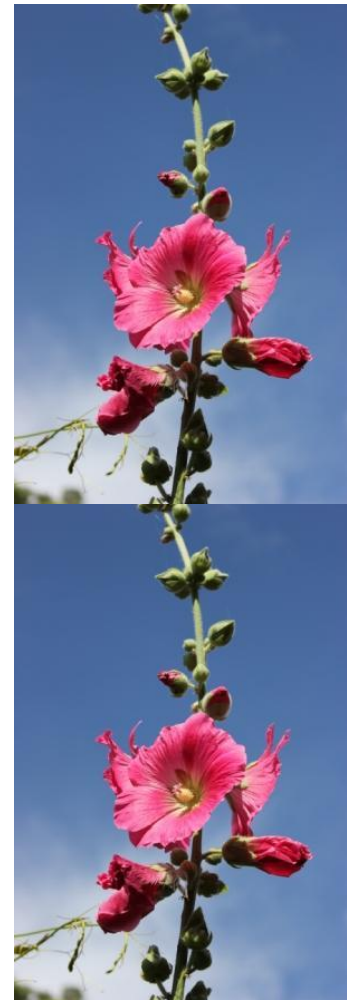
*World Health Organisation Reports 2008 - Primary Health Care (Now More Than Ever) , Global status report on non-communicable diseases 2010 , 2010 Health Care Financing*

# The hidden places:

- Those for which there is little public gaze,
- Those which only a few are ‘privileged’ or ‘eligible’ to enter,
- Those that we chose to conceal,
- Those that are “hidden in plain sight”.

*“Places are doubly constructed: most are built or in some way physically carved out. They are also interpreted, narrated, perceived, felt, understood, and imagined “*

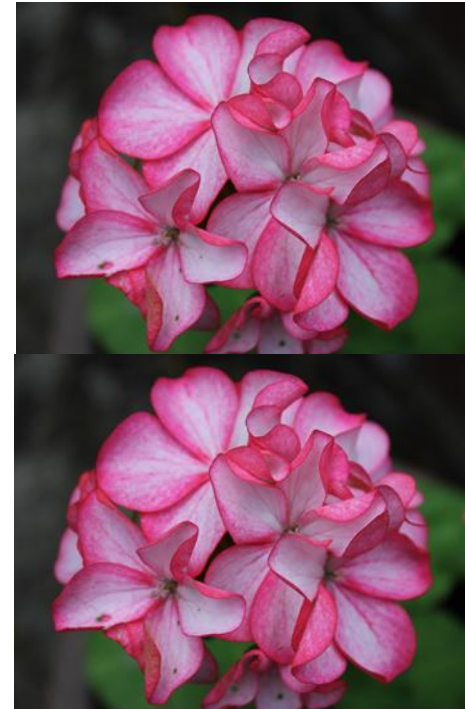
Soja EW. 1996. *Thirdspace: Journeys to Los Angeles and Other Real-and-Imagined Places*. Cambridge, MA: Blackwell



# Research in hidden places at this conference

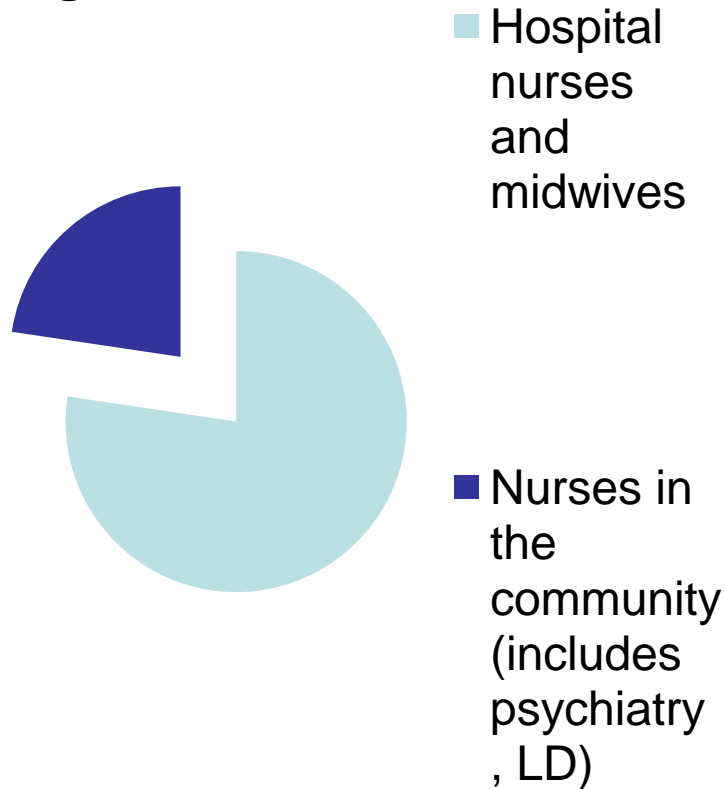
## Some examples

- Service responses to domestic abuse (violence to the person)- Caroline Bradbury-Jones , Julie McGarry ,
- Work with stigmatized women – Debra Jackson,
- Motivations of perpetrators of abuse to vulnerable adults – Robert Jenkins ,
- Factors in front line casualty care in Afghanistan- Alan Finnegan



# Nurses' gaze: "home" is hidden to most

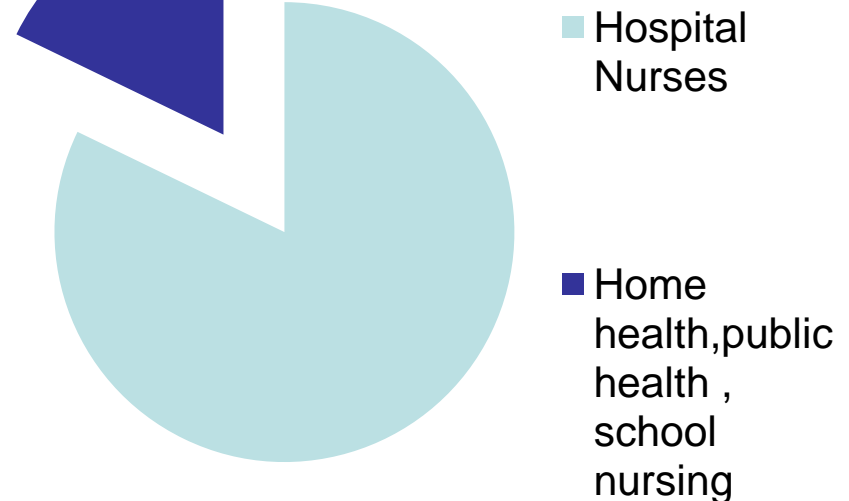
## England 2012



Source NHS Information Centre 2012

*"Two thirds of the nurses in Australia work in acute hospital settings"* Wendy Chaboyer March 21<sup>st</sup> 2013

## USA 2008



Source Registered Nurse Survey 2008

# EVIDEM Changing practice in dementia care in the community: developing and testing evidence-based interventions, from timely diagnosis to end of life – £2 million pounds over 5 years

**Steve Iliffe** (General Practitioner, University College London), Chief Investigator,

**James Warner** (Consultant Old Age Psychiatry, NHS Trust),

**Claire Goodman** (Nursing & Health Services Research, University of Hertfordshire),

**Jill Manthorpe** (Social Work, Kings College London),

**Vari Drennan** (Nursing, Health Care & Policy Research, St George's University of London & Kingston University),

**Greta Rait** (General Practitioner, UCL)

**Martin Knapp** (Health economist, London School of Economics)

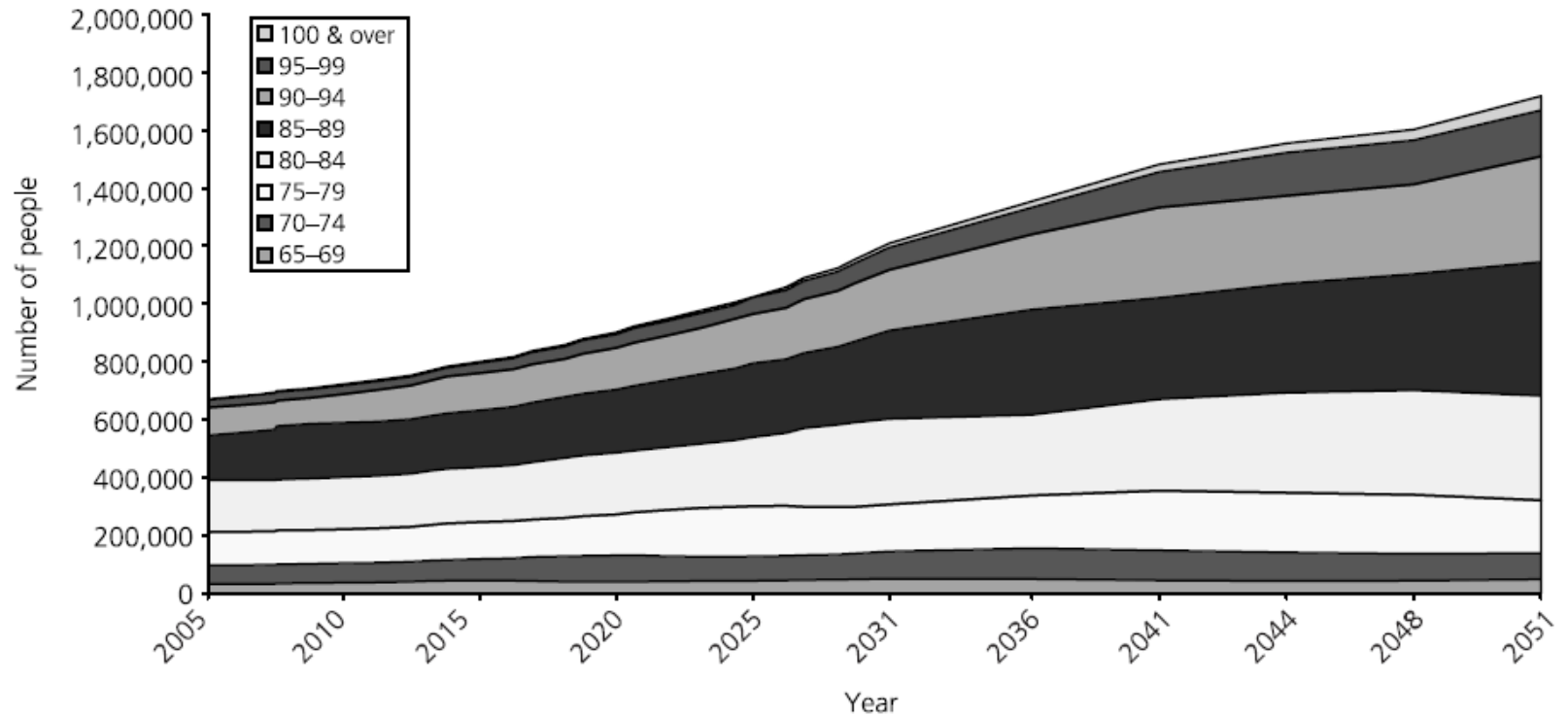


# Dementia Syndromes

- Increasing numbers world wide ,
- A disease course that is one of progressive loss to death,
- More than two-thirds of people with dementia live in their own or a relative's home,
- A small number of countries have “ Dementia Strategies/Policies” .



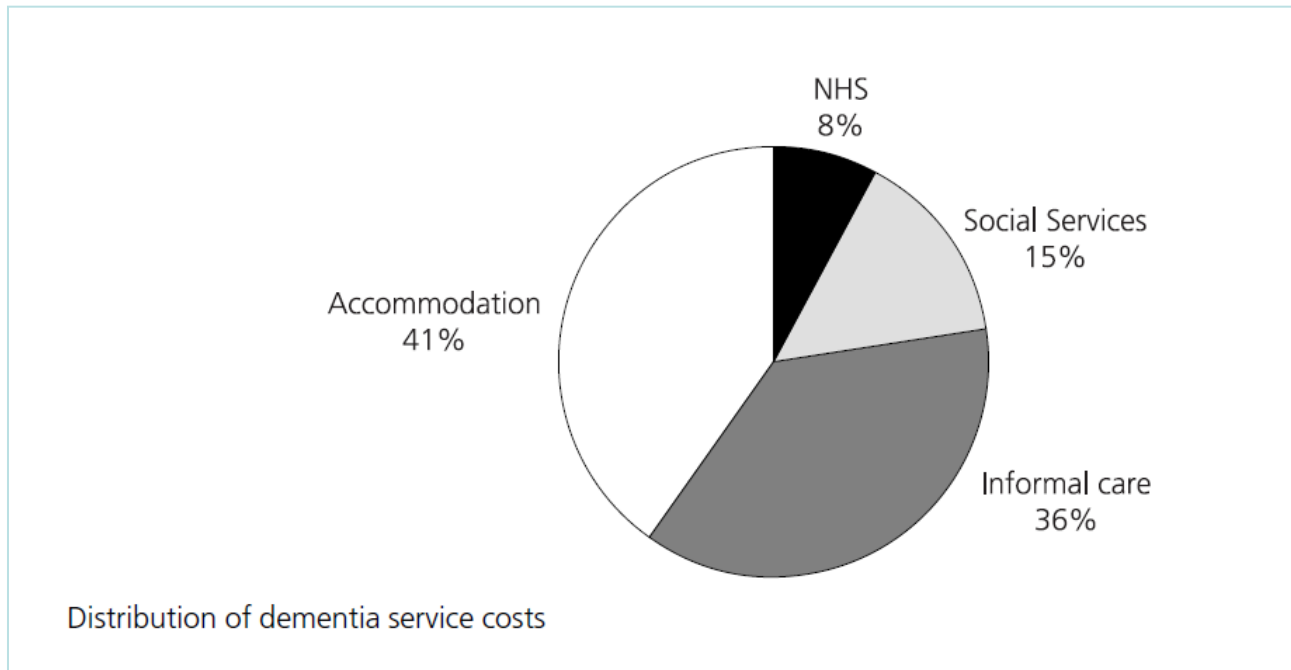
# United Kingdom



Projected number of people with late onset dementia by age group (UK)

From Dementia UK 2007 Knapp M and Prince M

# UK : distribution of dementia costs



**Dementia : total societal costs £17.8 billion (Knapp and Prince 2007)**

All cancers : societal costs £15.8bn. (Leal et al 2012)

Stroke : total societal costs of £8.9 billion a year ( Sakai et al 2009 )

# EVIDEM-C Continence promotion and incontinence management for people living at home

Why ?

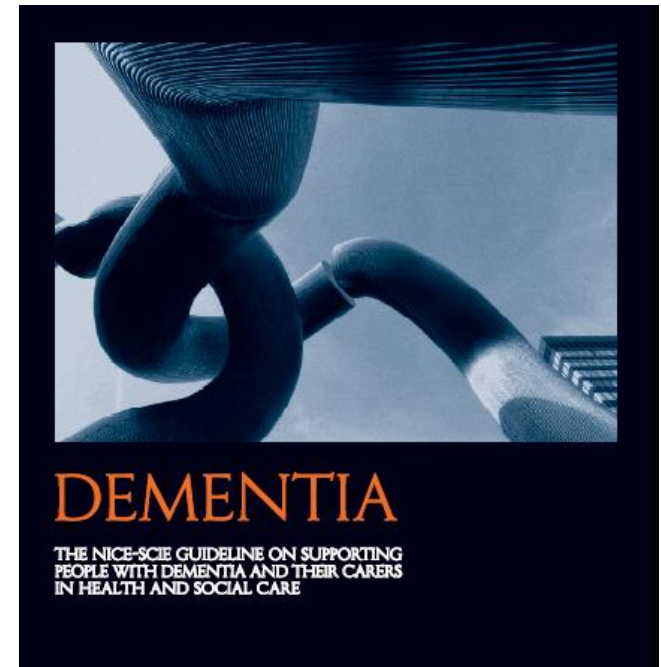
Incontinence problems in people with dementia have been identified as one of the significant factors in increasing family & carer burden and triggering the decision for moving to a care home

(Ouslander 1990, Hope et al 1998, Thomas et al 2004).



# The hidden place of people with two sets of symptoms

- The NICE- SCIE guideline on supporting people with dementia and their carers (National Collaborating Centre for Mental Health 2007) does not review evidence in relation to continence promotion,
- Incontinence assessment and management guidelines do not include people with dementia (NICE, SIGN, ICS etc) .



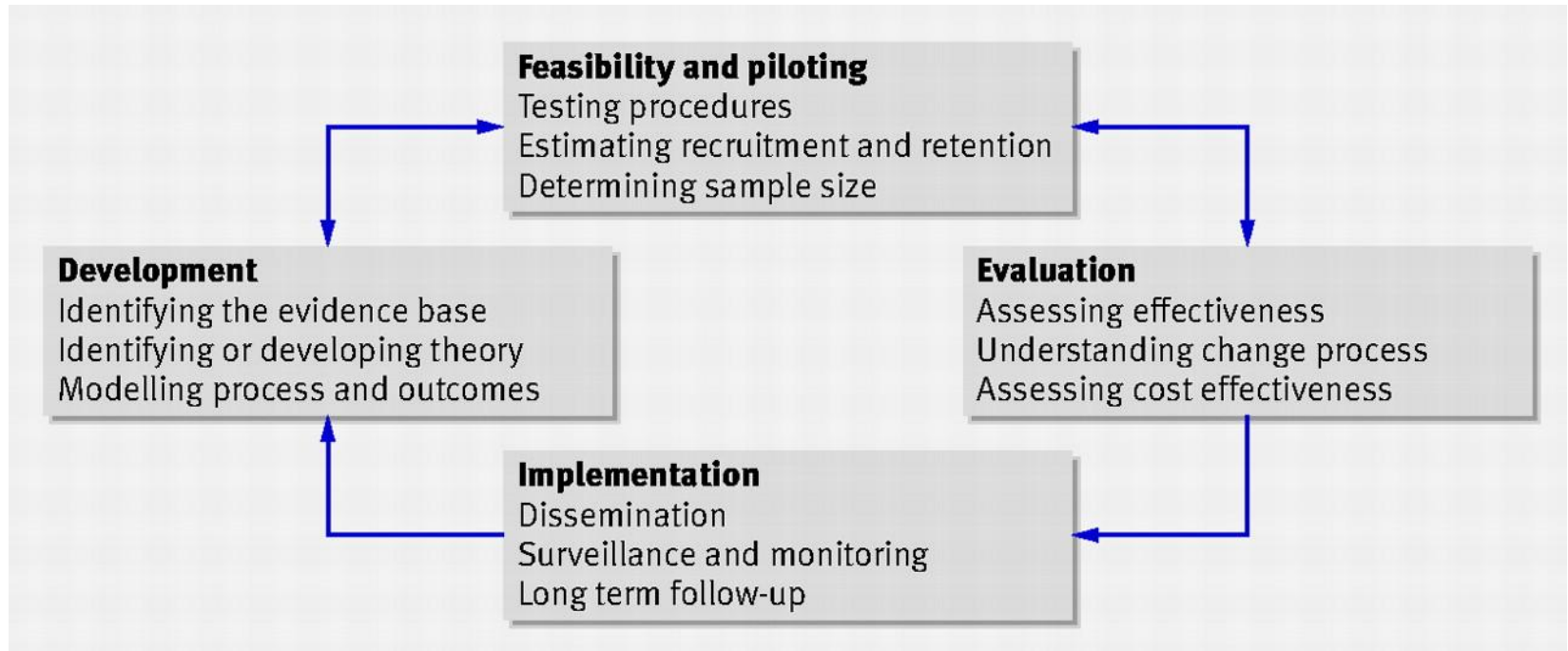
# The questions:

- Prevalence and incidence ?
- Effective strategies and from whose viewpoint ?
- What are the experiences, strategies, impact and cost consequences over time ?
- What is the feasibility and acceptability of developing specific interventions ?



# Developing and evaluating complex interventions

Fig 1 Key elements of the development and evaluation process.



Craig P et al. . Developing and evaluating complex interventions: the new Medical Research Council guidance *BMJ* 2008;337:bmj.a1655

**BMJ**

# Stigma

‘Mark of disgrace associated with a particular circumstance, quality, or person’ *Oxford English Dictionary*

‘Stigma is an attribute, behaviour, or reputation which is socially discrediting in a particular way: it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal one’ *Erving Goffman 1963*





# Urine , faeces , social mores and taboos

“Dirt” in all cultures is matter out of place ,

Across cultures excreta, and in particular faeces, are linked with danger, defilement, taboo and pollution.

(*Douglas M. Purity and Danger: An analysis of concepts of pollution and taboo 1966*).



# EVIDEM-C overview

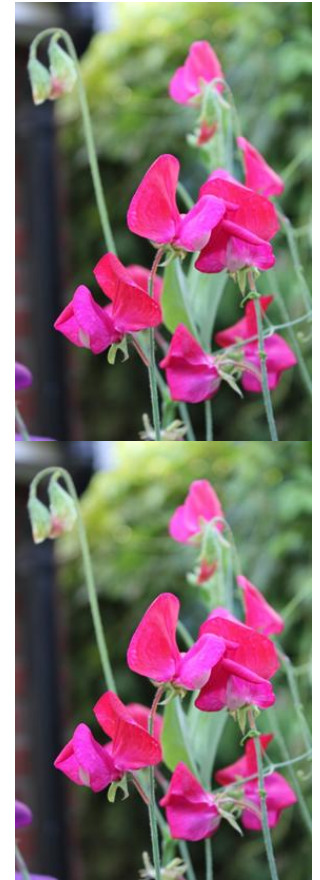
Phase 1	Phase 2	Phase 3
<b>Exploring the evidence</b>	<b>Testing feasibility and acceptability of suggested strategies</b>	<b>Developing and testing resources for practice</b>
<p>1. Review of research evidence</p> <p>2. The views on issues and strategies from people with dementia, informal carers and professionals</p>	<p>5. Exploring methods of investigating effectiveness and acceptability of different types of absorbent pads</p>	<p>6. Developing and testing continence assessment and care planning tools which address the problems of people with dementia, and their carers, living at home.</p>
<p>3. Review of NHS community health service policies and clinical guidance on incontinence</p>		<p>7. Resource materials for health and social care staff that links the problems of dementia with the problems of toileting and incontinence for those living at home.</p>
<p>4. Following experiences of people with these problems and their family carers over time</p>		

# Hidden in plain view - what is the prevalence in people with dementia living at home ?

Country of study	UI	FI	Sample
Hong Kong	21% of 197	18% of 197	Psycho-geriatric service users
Italy	38% of 5372		Home care recipients only
Ireland	34% of 82	27% of 82	Psycho-geriatric out patients
Canada	10% of		Home care recipients only
Japan	1.1%.of 1405		Community population
<b>USA*</b>	<b>24% of 184</b>		<b>Spouses of stressed carers</b>
UK	8.8% of 2,465		Community population
USA	11% of 56		Psycho-geriatric out patients

# Hidden from public gaze- what is the incidence ?

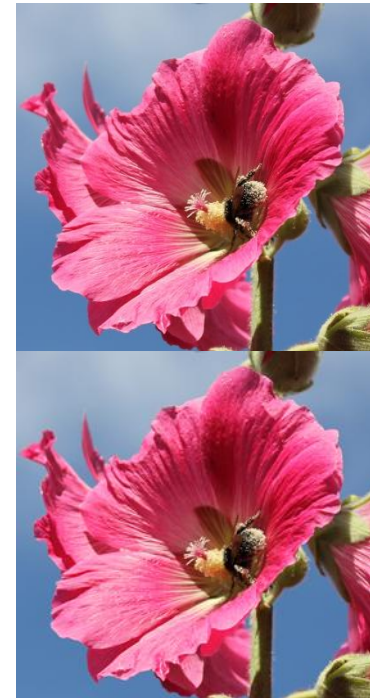
- A cohort study of patient data from The Health Improvement Network (THIN) ,
- There were 1,246,963 eligible participants from 487 general practices. The cohorts comprised 54,816 people with dementia and 205,795 people without.
- The incidence rates (95% confidence interval) for urinary incontinence in the dementia cohort were: **42.3** (40.9 to 43.8) in men and **33.5** (32.6 to 34.5) in women per 1000 person years at risk (PYAR) .
- In the non-dementia cohort, the rates were **19.8** (19.4 to 20.3) PYAR in men and **18.6** (18.2 to 18.9) PYAR in women.



From Grant et al. forthcoming

# Hidden from public gaze - effective strategies with this population ?

- Systematic review identified 3 studies testing interventions with this population,
- All involved advising/teaching carers ,
- 1 was of problem solving techniques by an Occupational Therapist ,
- 2 used a form of “prompted voiding” and involvement of clinical nurse specialists,
- None provided evidence of effectiveness.



*NB Prompted voiding continues to appear in guidelines irrespective of setting .*

From Drennan et al. 2012 BMC Geriatrics

# Hidden in plain sight : local guidelines for community nurses ?

- Documentary review of examples from every region of the England – public domain and in response to request
- Covered 38 local primary care areas
- Majority perfunctory reference to dementia
- Only 3 gave any detailed guidance



From Drennan et al. 2011 epub 2013 print Journal of Clinical Nursing

# Hidden places - those we chose to conceal- What are the strategies ?

- **Guided conversations** with people with dementia – over 12 months to recruit 7 people
- The descriptions of embarrassment and shame are no different from those given by other adults to ‘accidents’ and incontinence.
- The desire to protect spouses or other family members from the ‘pollution of bodily waste’ – unintended consequences



Cole et al. forthcoming

# What are the strategies , experiences and impact ?

- **Interviews with carers , including over time** – 15 months to recruit 32 people ,
- Range of problems reflecting the course of the dementia
- Preservation of the dignity of the person by not seeking help from health professionals
- Problematic to find strategies acceptable and appropriate – especially from different viewpoints
- When they did ask for help and information – often not forthcoming





## Compensating for losing independence in daily activities

*“...she used to go to the toilet and she didn't clean herself properly. And she wasn't aware of the fact, you know, she was going to the toilet. I took her for the bowels and she wasn't wiping her bottom, wiping herself properly, her hands got....I thought oh my god. So I had to do that for her. I took over that role”.*

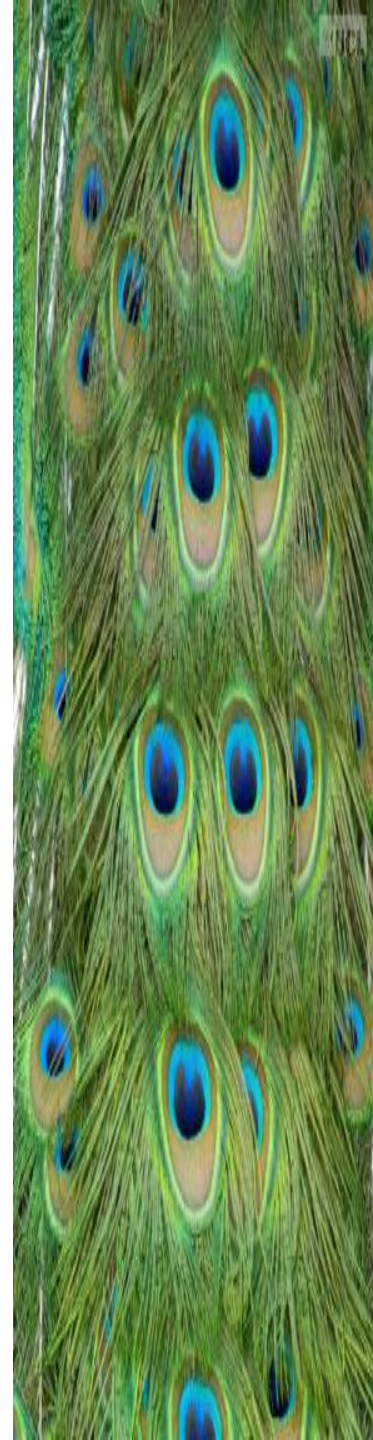
*Carer 18 (spouse)*



# Preserving identity and dignity, personhood.

*“I’d didn’t want to talk to anyone about it [the toileting difficulties and incontinence]... she was always such private person, she was always neat , cared so much about how she looked and dressed..”*

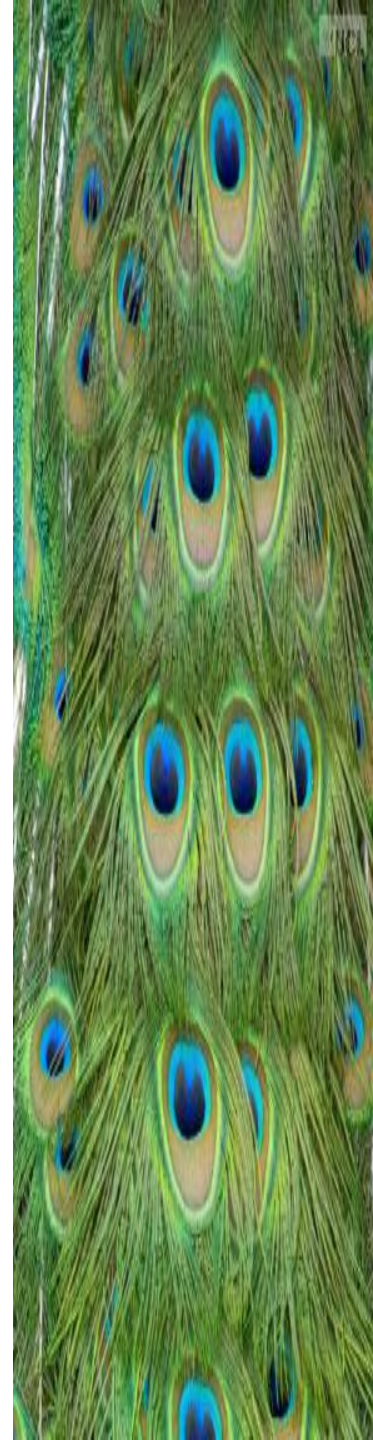
*Carer 7 (spouse)*



## Managing Intimate Activities and Excreta

*'Yeah, that was the worst thing for me [the person able to unable to clean after defaecation], everything else I can cope with but I suppose, if you're not used to it, that's the only side of things - the very basic cleanliness. Even though you've had children, doing it with an adult is different, isn't it? I mean for a start, there's more of it (laughs).'*

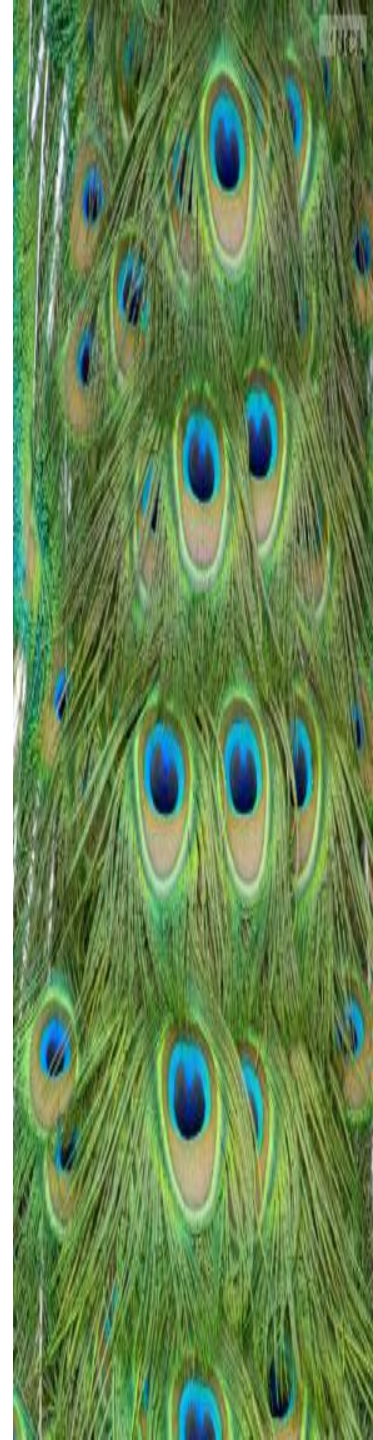
Carer 8 daughter in law



## Managing intimacy and excreta

*'Well now mum needs help to go to the toilet my sister wont let me keep company with her on my own. She wont , my sister , wont talk about it. She just says I cant help mum, its not right and I cant be the one to be there in an evening and give her a break . We've had the most god awful rows " .*

Carer 25 son



## Matter out of place

*'Yeah, it was awful. She wouldn't know she had poo on her hands and then she'd wipe it off everywhere.*

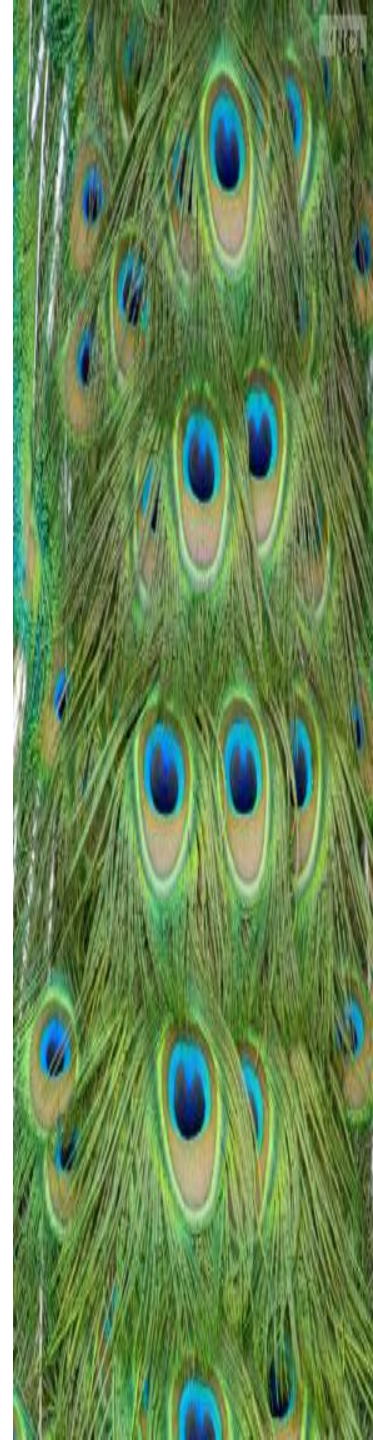
*So me and me sisters took it in turns to go there everyday and wipe everything down with bleach but we stopped the kids going round . It wasn't nice for them and she'd want to give them drinks and snacks , you know, but you just wouldn't know where her hands had been or what was on 'em”.*

Carer 21 daughter



## Stigma by association

*“I had to carry the used pads ....you know he was doubly incontinent , so with faeces in .... in the black bags out the flat to the rubbish chute and I’d be terrified I’d meet a neighbour and I felt horrible carrying all this dirty stuff and have to speak to them . It got to where I couldn’t do it anymore. It sounds stupid , I've been a nurse and all but I just couldn't carry them out the flat past everyone”.*



## Managing Behaviour

*'Oh my God. The problem is she doesn't like people touching her. She knows she wants to go to the toilet, you get her there, then she doesn't want to pull her trousers down, so you have to start, you have to do it, so she's going to fight.....If she gets your fingers she'll try and break them. ...*

Carer 18 daughter

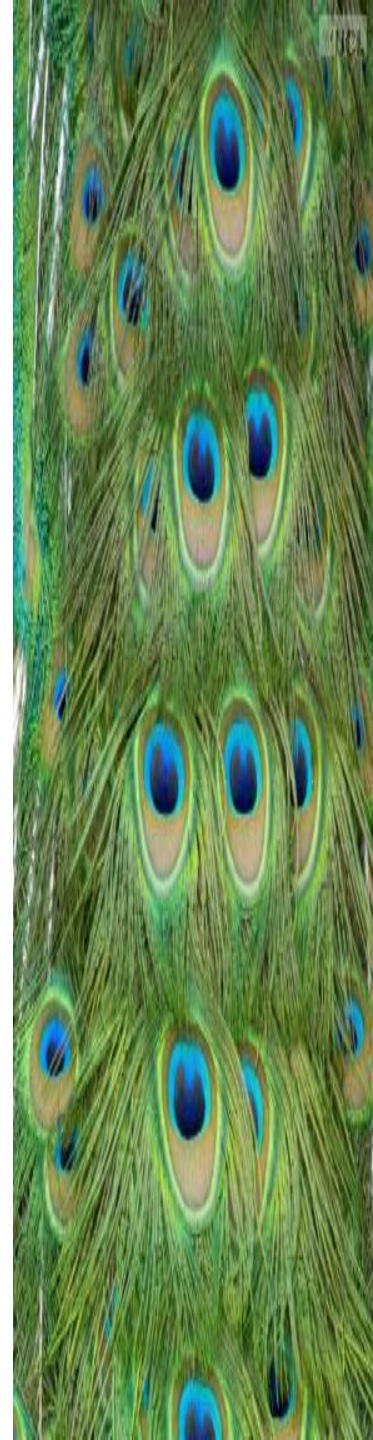


## Strategies : in whose interests ?

*“Ok so what I do to stop him taking down his trousers and ‘going’ on the chair during the day and when no one is here, is, I put him in his trousers with the belt on back to front so he cant undo it .*

*It means he has to use the pad so when I get here I just have to take the pad off and not clean down all the furniture . You tell others back to front belts that the answer”.*

*Carer 28 daughter*





## Strategies : in whose interests ?

*“Even so, a couple of them (formal carers) can’t get her in the toilet without, you know, real force being used. And for a long time I was very worried about that but I don’t anymore because what will happen if I, sort of let, her go ? for instance if she’s just come out of the toilet and then I’d have the trouble [incontinence] just the same. So I tend to use a lot of force and a lot of strength to get her in there.”*

Carer 15 spouse

From Drennan et al BMC Geriatrics 2011

Winner of Royal College of General Practitioners Research Paper for the Year 2011 Category Neurodegenerative Diseases



# What interventions to develop and test ?

- Tools to aid primary care responsiveness to continence problems
- Feasibility work on effectiveness of different designs of continence pads

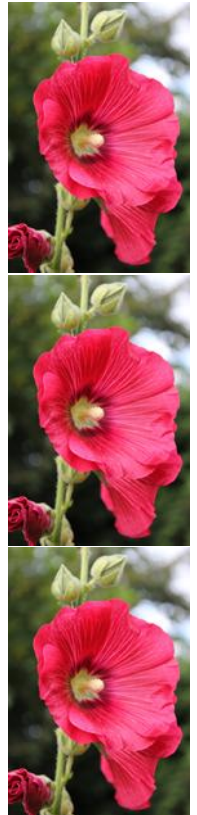


# EVIDEM-C Dementia-focused Continence Assessment Add-on Tool

- the EVIDEM-C Dementia-focused Continence Assessment Add-on Tool has been developed based firmly on service user perspectives
- Modified Delphi process suggests –
- Good face validity
- Some content validity but this needs further testing

## **NEXT STEPS:**

- Testing the EVIDEM-C tool in the field
- Searching for examples of such dementia focused community nursing tools from other countries



# EVIDEM-C (3): Effective containment

A feasibility study to investigate the acceptability, effectiveness and associated costs of different types of absorbent products used for incontinence by people with memory problems living at home



# Indicators

Ease of putting on – by day
Ease of putting on –by night
Leakage
Stay in place
Contains smell
Discreet
Dry comfort
Wet comfort
Keep skin dry
Overall opinion for day use
Overall opinion for night use

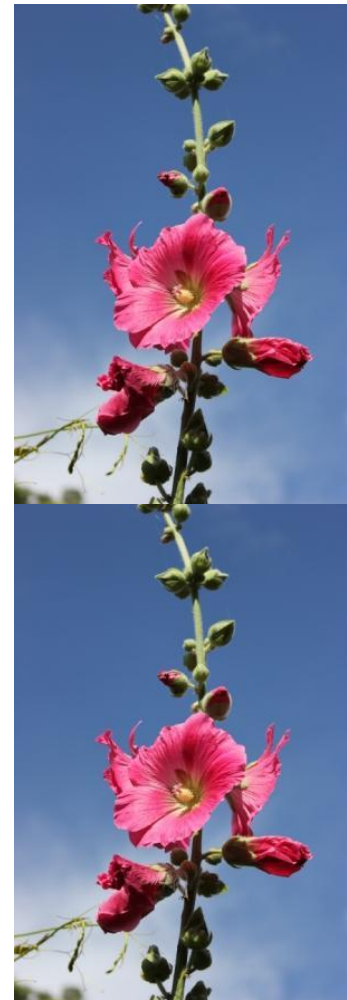


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# Did I meet the plenary objectives ?

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**Respond**  
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or agree

# Thank you for listening

For more information please contact Vari Drennan

[v.drennan@sgul.kingston.ac.uk](mailto:v.drennan@sgul.kingston.ac.uk)

Drennan et al. A taboo within a stigma. A qualitative study of managing incontinence for people with dementia living at home. BMC Geriatrics 2011, 11:75.

- Drennan *et al.* Addressing incontinence for people with dementia living at home: a documentary analysis of local English community nursing service continence policies and clinical guidance Journal of Clinical Nursing 2013 Feb;22(3-4):339-46. doi: 10.1111/j.1365-2702.2012.04125.x. Epub 2012 Jul 13.
- Drennan *et al.* Conservative interventions for incontinence in people with dementia living at home: a systematic review BMC Geriatrics.2012, 12:77. DOI: 10.1186/1471-2318-12-77 Published online 27 December 2012
- Drennan *et al.* The prevalence of incontinence in people with cognitive impairment or dementia living at home: a systematic review Neurology and Urodynamics Article first published online: 5 NOV 2012 | DOI: 10.1002/nau.22333
- *This presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-060-1005). The views are those of the speaker/authors and not the NIHR, NHS or Department of Health*