

NHS Research Scotland Annual Conference

Parallel Sessions

Patients at the heart of research



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 @NHSResearchScot

 #NRSConf18



University
of Glasgow

PPI in nursing and health care research: palliative and end of life care

Professor Bridget Johnston

Florence Nightingale Clinical Professor of Nursing,
University of Glasgow / Greater Glasgow
and Clyde

**INSPIRING
PEOPLE**

Our research University of Glasgow

The Team

Professor Bridget Johnston

Dr Lisa Kidd

Dr Grigorios Kotronoulas

Dr Mark Cooper

Dr Joanne McPeake

PhD Students

Annabel Farnood

Bahaa Alassoud

Maria Drummond

Saengrawee Thanthong

Bella Purpa

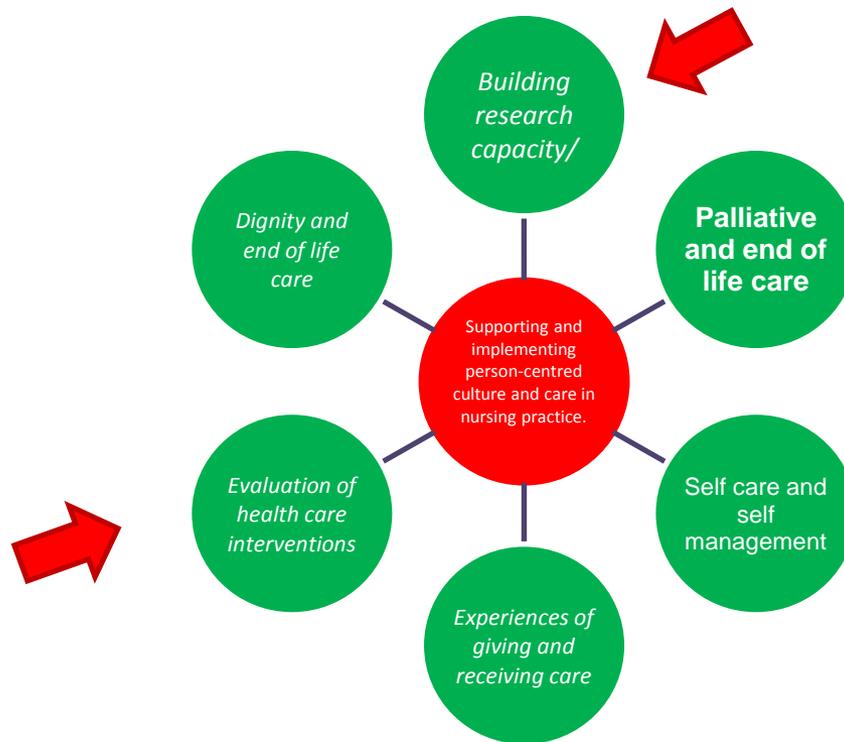
Lindy Morrison



Unive
of Glas



research programme



- Developing an intervention for carers of people with life limiting illness – Glasgow (funded endowment NHS Greater Glasgow and Clyde- PhD studentship)
- Differential Diagnosis Support Systems: an analysis of potential solutions for new roles in out of hours and primary care (funded Scottish Government)
- Evaluation end of life care in prisons Macmillan Cancer Support

- Feasibility/pilot study to assess the use and acceptability of the Playlist for Life personalised music intervention as a means of enhancing personhood and legacy with adults at end of life in the hospice setting
- Improving the implementation of personhood/legacy-promoting interventions in the delivery of evidence-informed, person-centred dementia care in Scotland
- Improving oral care in older adults in hospital

PPI group University of Glasgow- palliative and end of life care

- Established 2017
- 2 grants- UofG Kickstarter grant
- Elizabeth Stanfield Bell Wilson Scholarship ICAMS
- NIHR testbed 2018
- Event May 2018
- 20 members all living with life limiting illness or caring for someone with life limiting illness.
- Contribute in variety of ways- meeting face to face, email, phone, skype

EVENT PROGRAMME

Public Involvement in Nursing and Healthcare Research

A community-based event to promote patient and carer involvement in Palliative and End of Life Care research at the Nursing and Health Care School, University of Glasgow



Renfield St. Stephen Centre, 260 Bath Street, Glasgow, G2 4JP

Tuesday 15th May, 2018, 10.00am – 2pm

Kirk Lounge (1st Floor)

Organised by:

Dr. Gillian Mathews

Event Programme

- 10.00am Arrival and refreshments
- 10.15am Welcome and Introduction to PPI event
University of Glasgow - **Professor Bridget Johnston**
- 10.25am Patient & Public Involvement (PPI) - **Dr. Gillian Mathews**
- 10.40am Workshop 1 What is Public Involvement
mean for me?
- 11.40am Ayrways Choir
- 12.00pm Lunch and Social Chat
- 12.45pm Research activity in the Nursing and Health
Care School
Professor Bridget Johnston
- 13.00pm Workshop 2 - Identifying priorities for
research
Dr. Gillian Mathews
- 13.45pm Summing up/Reflection/Questions/Answers
Involvement

Ways our group involved

- Identify priorities for research
- Help to develop research proposals
- Work as part of a team to oversee a research project
- Become a co-researcher –gathering data, e.g. interviewing people, looking at findings from the research and helping to
- decide on the key themes
- Sharing findings with others

Benefits

- Increase research knowledge and skills
- Increase knowledge of palliative and end of life care
- Focus on personal stories
- Feeling useful, empowered, contribution valued
- New friendships
- Assertiveness with clinicians
- Financial rewards

Standards for Public Involvement Palliative and End of Life Care

Aims:

To increase the scope and diversity of PPI membership and activity

Co-produce:

- A Code of Practice for public involvement in palliative and end of life care research
- A 3-year research plan to take research forward in the Nursing and Health Care School

National Standards for Public Involvement

Standard 1: **INCLUSIVE OPPORTUNITIES**

We offer public involvement opportunities that are accessible and that reach people and groups according to research needs.

Adverts – meeting with community groups

Standard 2: **WORKING TOGETHER**

We work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships.

Joint grant/user led- flexible ways of working

Standard 3: **SUPPORT & LEARNING**

We offer and promote support and learning that builds confidence and skills for public involvement in research.

Joint visit to London for test bed meeting, event May, further events- joint presentations

National Standards for Public Involvement

Standard 4: **COMMUNICATIONS**

We use plain language for timely, two way and targeted communications, as part of involvement plans and activities.

Joint lay summaries- co produce leaflets etc

Standard 5: **IMPACT**

To drive improvement, we capture and share the difference that public involvement makes to research.

Presentations/ blogs/articles

Standard 6: **GOVERNANCE**

We involve the public in our governance and leadership so that our decisions promote and protect the public interest.

Working together

What might the drawbacks be?

- Meaningless or tokenistic involvement
- Research can take a long time so results may not be seen immediately
- Lack of clarity about role and level of involvement
- Frustration and difficulties with participation due to other commitments and possible ill-health
- The time involved to build relationships and learn new skills
- Disagreements between researchers and service users

Bridget.Johnston@glasgow.ac.uk

 **@BridgetJohnst**

Thank you

**INSPIRING
PEOPLE**

 /glasgowuniversity

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Search: University of Glasgow

Research, #Huh?

**Promoting Research Awareness
in NHS Grampian.**

Emma Berry and Mariella D'Alessandro

Why?



- ▶ **Poor image of clinical trials**
 - **Image of being the “guinea pig”**

Novartis sued by bird flu guinea pig

HSN1 VACCINE ALLEGATIONS

By swissinfo.ch and agencies

Health Law and order

JUL 13, 2017 - 15:55

Ten years ago Swiss pharmaceutical giant Novartis commissioned clinical trials for a bird flu vaccine which ended up being carried out on homeless people in Poland. One man, who says they were told they were being tested for a conventional flu vaccine, is now suing the Basel-based company.

When the H5N1 virus broke out among birds in Europe in 2005, scientists feared it could be transmitted from human to human and cause a pandemic. The pharmaceutical industry across Europe rushed to develop a vaccine.



Scientists feared the H5N1 virus could



THE Sun TV & SHOWBIZ | NEWS | FABULOUS | MONEY | MOTORS | TRAVEL | TECH

Human guinea pigs disfigured by 'Elephant Man drug trial' tell of limb loss horror

Six men took part in 2006 drug trial which left them screaming in pain, organs failing, head swelling, projectile vomiting and amputation of fingers and feet

VIDEO By GEORGE SANDEMAN
18th February 2017, 3:19 pm | Updated: 19th February 2017, 9:24 am



9 COMMENTS

SIX men who suffered horrific side effects in a drugs trial that went wrong a decade ago have spoken out in a new documentary.

In March 2006 eight men volunteered to try a new drug that researchers hoped would manipulate the immune system and significantly improve cancer treatment.

Bill Clinton what Jean-Claude Juncker... | Linzma learns F. Gordon Puzos's plan... | Sterling to RBC-K1 in 2018 as market le... | Fares O'Hara led by Inge ending change... | Morgan drops MAJOR bombshell about her...

STATIN WARNING: Patients 'used as guinea pigs' - shock claim from experts

PATIENTS prescribed statins are being used as unwitting 'guinea pigs' because the side effects have not been properly investigated say experts.

By LUCY JOHNSTON
PUBLISHED: 09:02, Mon, Oct 9, 2017 | UPDATED: 11:26, Mon, Oct 9, 2017

SHARE f TWEET G+ Email

Leading cardiologist says there are concerns over statins



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Most read in Health



1 Diabetes type 2 - this £1 fruit could PREVENT high blood sugar



2 High blood pressure warning: Five activities and exercises bad for hypertension



3 Arthritis symptoms: Cooking food in this oil could increase joint pain and inflammation



4 Best supplements for preventing colds: These 15 a-day tablets could STOP viral infections



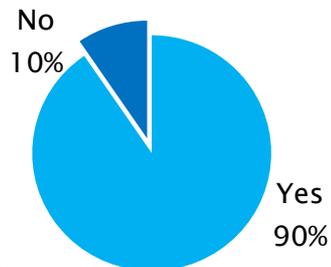
5 Prostate cancer symptoms: Difficulty getting an erection can

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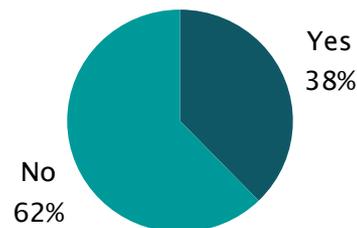
Background research

- **Search of current resources available**
- **Communicating with other PPE&I teams and departments**
- **Current Research Engagement and Awareness**

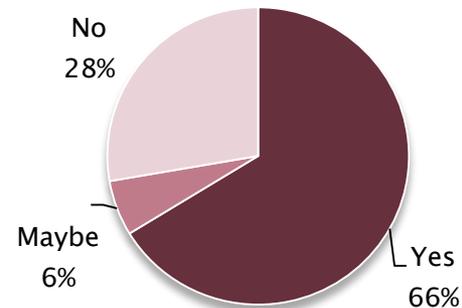
Have you heard of clinical research (including clinical trials) before?



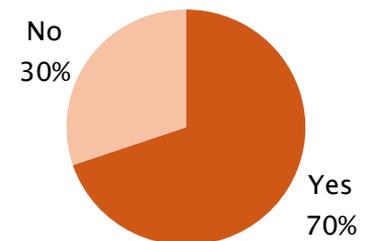
Have you ever been involved in clinical research?



Would you take part in clinical research?



Would you be interested in finding out more about clinical research?



What have we been doing?



- ▶ **A website to raise awareness & understanding**



What's in this website?



Animation video



What's in this website?



FAQs

- **Simple answers to common questions on research**
- **Linked to videos**

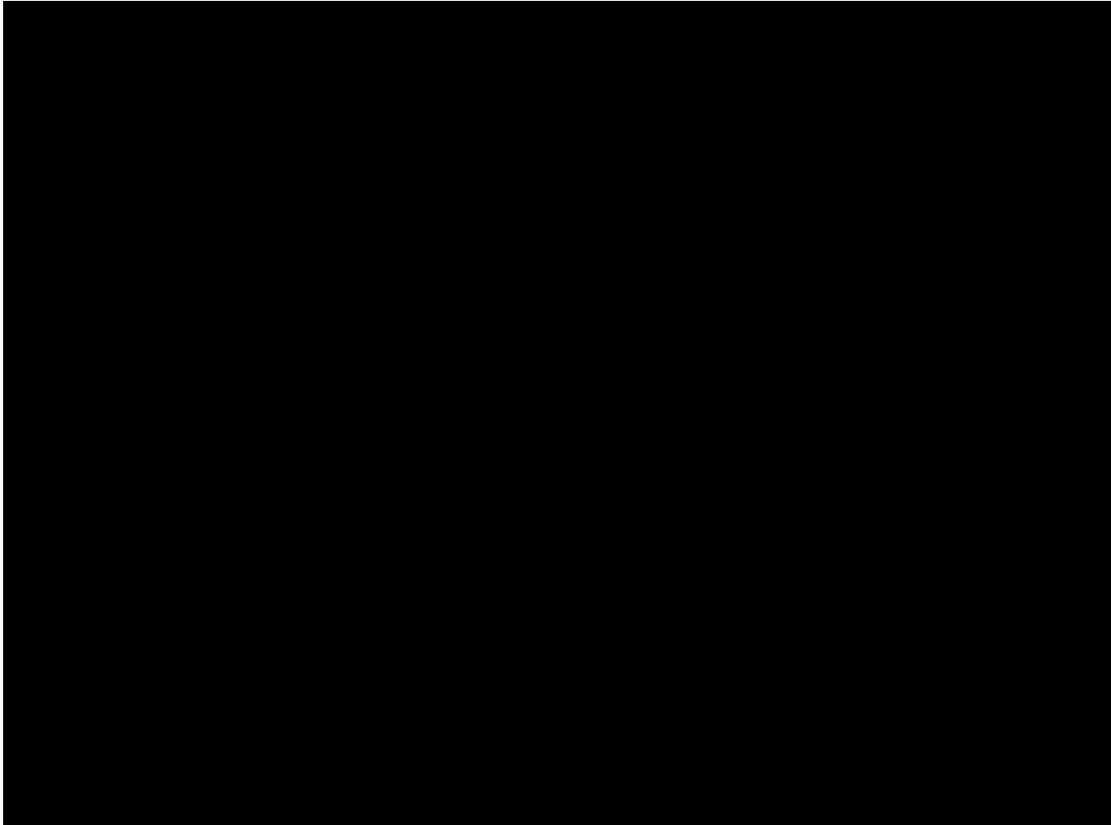
Database

- **Studies currently open to recruitment**
- **Limited information and linked to the UK Clinical Trials Gateway**



What's in this website?

- ▶ **Personal story videos**



Was taking part hard or were there any challenges?

What's in this website?

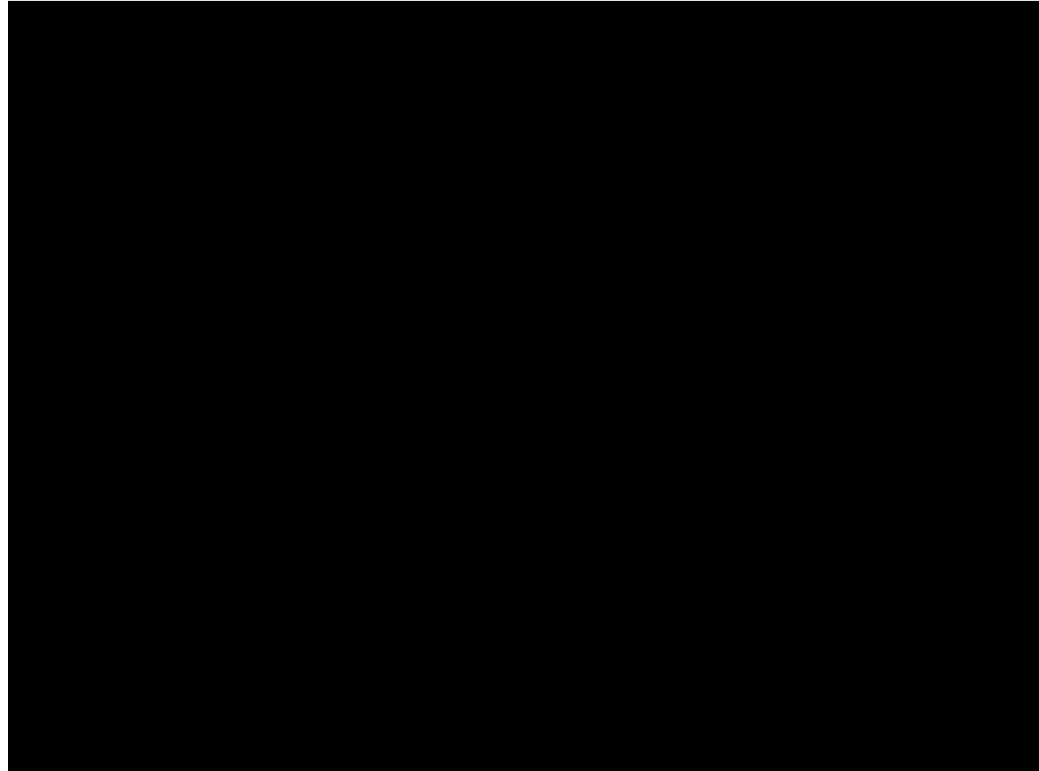
- ▶ **Personal story videos**



What are the important things participants need to know about research?

What's in this website?

- ▶ **Personal story videos**



What are the benefits of research?

How are we planning to promote this?



- ▶ **Resources to promote website**

- ▶ **Social media channels, internal communications and external media coverage (Corporate Communications approved)**

- ▶ **More public engagement activities**

- **MedCafe/Science talks at Waterstones etc.**
- **Working with PPE&I groups**

- ▶ **Evaluation plan to see impact of the website**

Website Development Feedback

Focus groups held for website feedback

Patient and Public

More videos of patient experiences

Real People Images preferred

Videos should have a balance between informative and personal

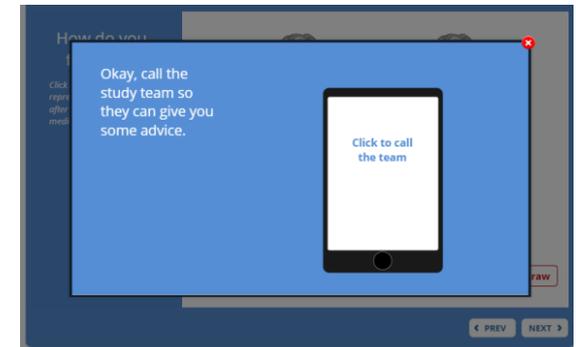
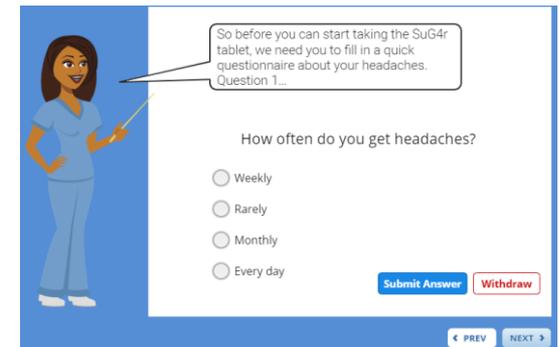
Mention the training involved in research roles

Show research success, and how research has changed healthcare

eLearning Module



- **Interactive Game Format**
- **Works well with new TURAS learn**
- **Can play as a pretend patient or a researcher**
- **Openly published and linked to website**



Widening our research community and supporting PPI



- ▶ **Changing how we communicate with new potential researchers**
- ▶ **Identifying PPI groups and resources**
- ▶ **Creating a PPI signposting resource**

Summary



- ▶ **Background research**
- ▶ **Website development with stakeholders involved**
- ▶ **Interactive eLearning module which works as a game**
- ▶ **Proactive approach to communicating with potential researchers**
- ▶ **Happy to share our learning and support others**