

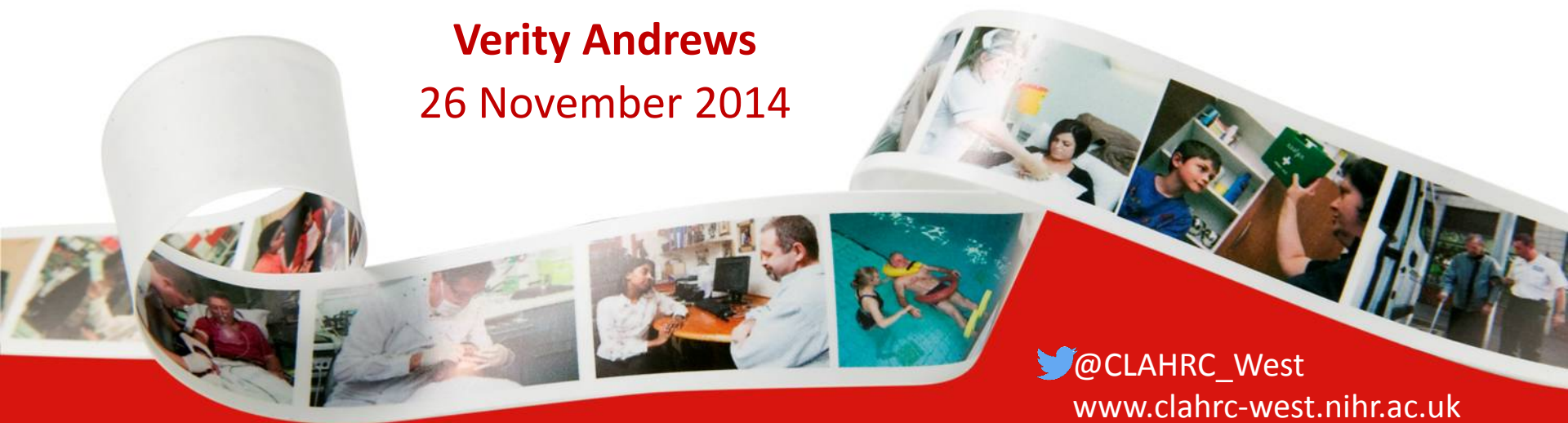
# REACH West: Research participation across the West

## NIHR CLAHRC West

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The logo for Reach West, featuring the word "Reach" in white above the word "West" in white, both set against a dark teal rounded rectangular background.

Reach  
West

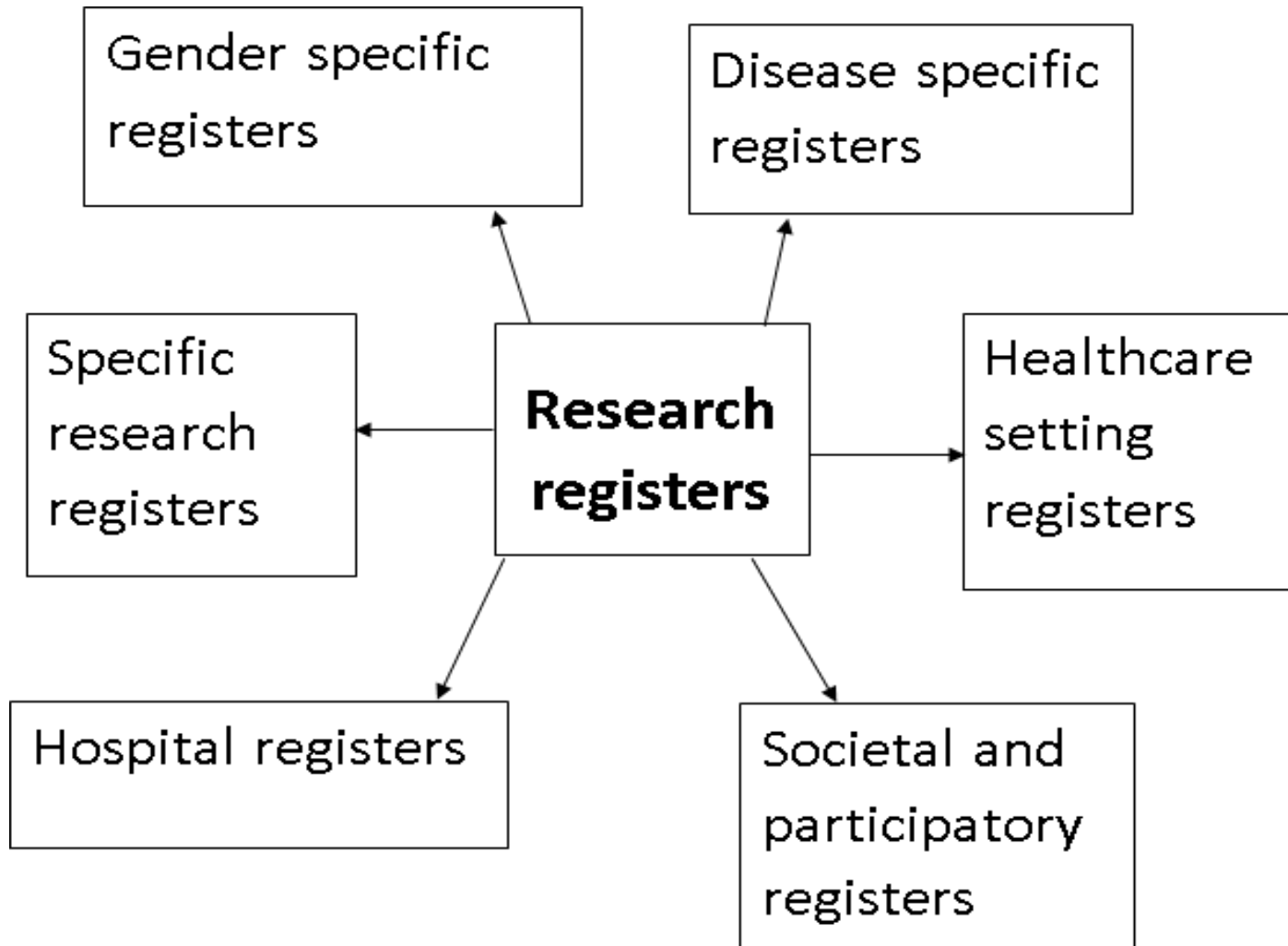
# Aim today

- Explain the reasons for setting up Reach West
- Introduce Reach West
- Present views about it from patients and clinicians
- Consider the challenges and prospects for its use across the West

# Background

- Research can be difficult
  - Access to potential participants, gatekeeping
  - Recruitment is often complicated and slow
- Patients and the public are keen to be involved
  - 69% indicated willingness (MRC survey)
- NIHR encourages research participation
  - WCLRN
  - “OK to ask” campaign
  - Patient and public involvement (PPI)
- No system to identify eligible people for research

# Types of research registers



# Public participation register

- Huge opportunities
  - For wide range of people and patients to be involved
  - Many different sorts of research studies, with controls

But...

- How can you obtain enough information?
  - Complete detailed questionnaire on entry
  - Consent to linkage with medical records



The screenshot shows the homepage of the SHARE website. At the top left is the SHARE logo, followed by the NHS Scotland logo. On the right, there are social media icons for Facebook, Twitter, and LinkedIn, and a search bar. Below the header is a navigation menu with links: SHARE, WHY I SHARED, REGISTER, WHY SHARE, WHAT'S NEW, ANY QUESTIONS?, GOSHARE, and GET INVOLVED. The main content area features a large banner with the SHARE logo and a photo of a woman, Lorraine. To the right of the photo is a call to action: "SAVE LIVES Sign up now. It takes less than a minute to submit your details" with a prominent green "REGISTER" button. Below this is a registration form with fields for NAME (Lorraine), AGE (32), HEALTH RECORD (Asthma), and WHY (Because knowledge is power). A social sharing bar shows "TELL YOUR FRIENDS" with "Like" (2.1k) and "Tweet" (496) buttons. Below the banner is a section titled "LORRAINE'S STORY" with three cartoon avatars and a "WATCH THE VIDEO" button. To the right is a counter showing "041817" people registered so far, with a "ANY QUESTIONS?" button. Below these are two columns of text: "WHAT'S NEW?" with two news items and "WHAT IS SHARE?" with a detailed description of the initiative and a legend of colored speech bubbles explaining the benefits.



THE VIDEO



041817

People registered so far



ANY QUESTIONS?






## WHAT'S NEW?

attended the NHS Highlan... //  
ghland held its Research,  
oment and Innovation Annual  
ence where SHARE was promoted...  
lore

launches at the Golden J... //  
nday 10th November SHARE was  
ed at the Golden Jubille National

## WHAT IS SHARE?

SHARE is a new NHS Research Scotland initiative created to establish a register of people interested in participating in health research and who agree to allow SHARE to use the coded data in their various NHS computer records to check whether they might be suitable for health research studies. This access can be incredibly useful when it comes to developing new treatments and cures for a wide variety of health conditions.

-  Improve future healthcare in Scotland
-  Research can lead to better treatments you and your family
-  Just sharing your details is enough to help
-  Option to participate in health trials if you
-  It's easy to sign up or opt out

# Patients' views

“I have had a good service out of the NHS, I am one of these that also believe in trying to put back what I have got out of society and if it helps the next person whatever is wrong with me hopefully it will help the next generation or the next person even”

Patient focus group P5

“I don't really see how your database will have any value if you couldn't link it to the person's medical records”

Patient focus group P2



# Clinicians' views

“I can see that it [the register] would make things much easier in terms of picking up on them [participants] at some later time even if this is a project that has not been developed at the time they consent”

Clinician focus group P6

I can't really see that there are any [patients that shouldn't be approached]; by excluding people who are [willing to participate], preventing them from taking part in research, that can be just as bad, they are not given the opportunity to do that”

Clinician focus group P2



# Reach West

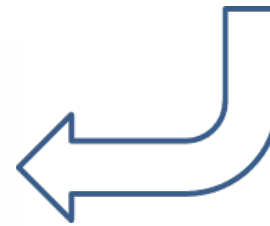
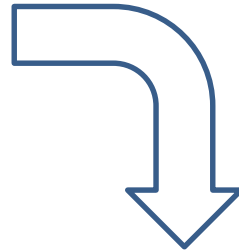
- A public participation register for the West
- Linkage of NHS medical and related records
  - Informed about relevant research projects
  - Provide anonymised data for research.
- A move away from passive to active expression of interest in health research
- Matches interested people to high quality research projects

- REC approval to go ahead
- Currently in feasibility phase
  - Establishing data linkage processes with one NHS organisation
  - Setting up secure databases and SOPs
  - Interviews with potential participants exploring
    - Suitability/acceptability of information provision
    - Willingness to use website or paper forms
  - Planning access to members of the public

- Patients and members of the public
  - Give consent to join Reach West and have data linked
  - Invited to participate in relevant research projects
    - Provide individual informed consent to take part
- Researchers
  - Apply to REACH West for help recruiting eligible participants or for anonymised data

All projects need full NHS or University ethics approval

# Future strategy





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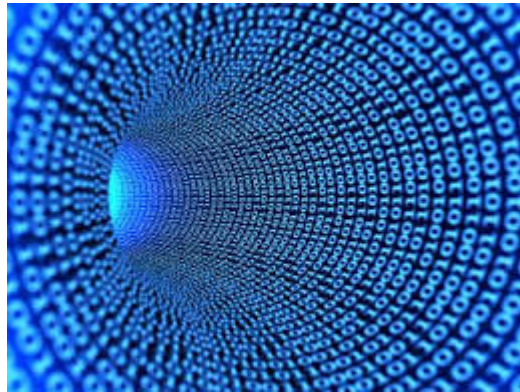
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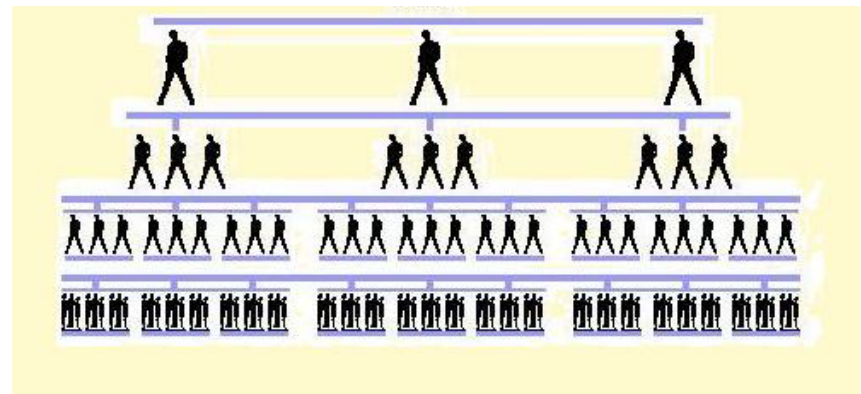
Frank Sullivan  
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Keith Milburn



Thank you to all the patients and clinicians who took part in the focus groups



# Reach West





*National Institute for  
Health Research*