

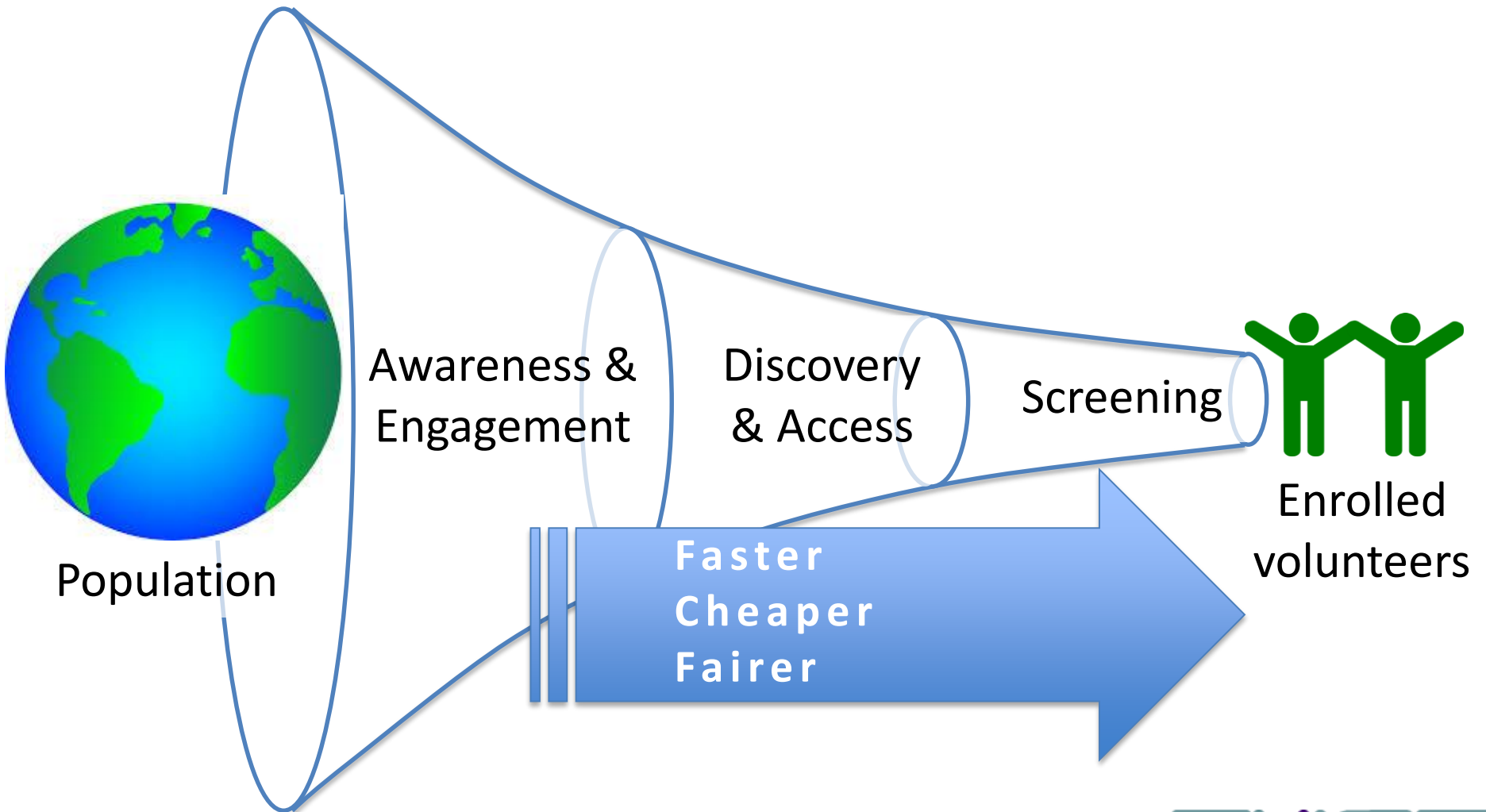
Engaging,  
effective,  
research...

or

Making Devon the  
best place for  
health innovation  
in the world?

Piers Kotting  
University College London  
University of Exeter Medical School  
NHS England Innovation Accelerator Fellow

# Matching the right people to the right research opportunities at the right time

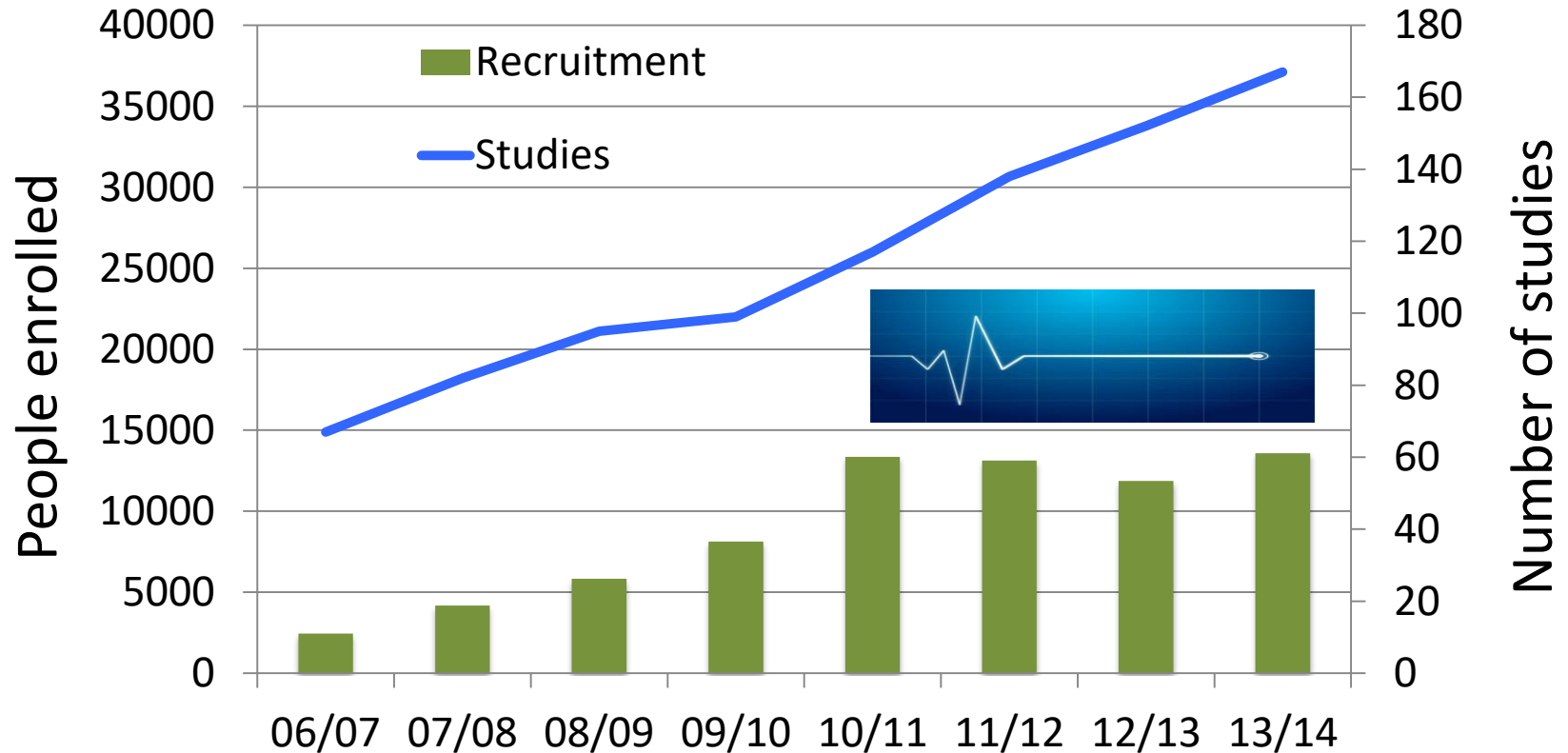




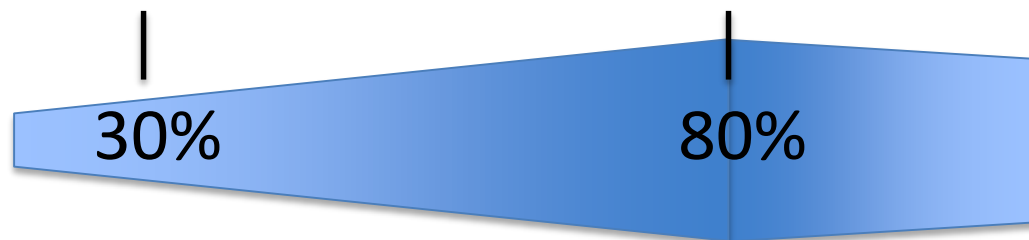
History  
may lead  
to new  
insights!!!

**Where did we come from?**

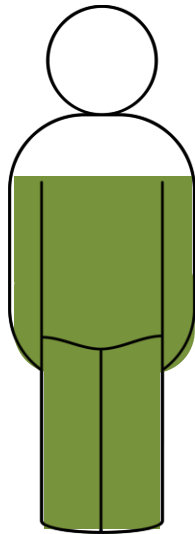
# Growth in UK dementia research 2006 - 2014



% studies  
delivered on  
time, to target:



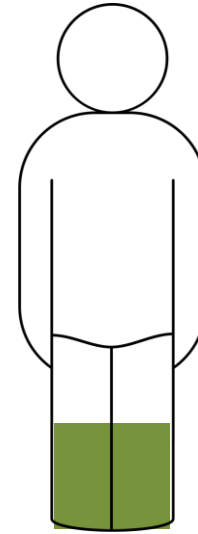
# And...



**62%**

Adults willing to take  
part in dementia  
research

Alzheimer's  
Research UK  
survey  
(2014)



**19%**

Adults know how to  
get involved

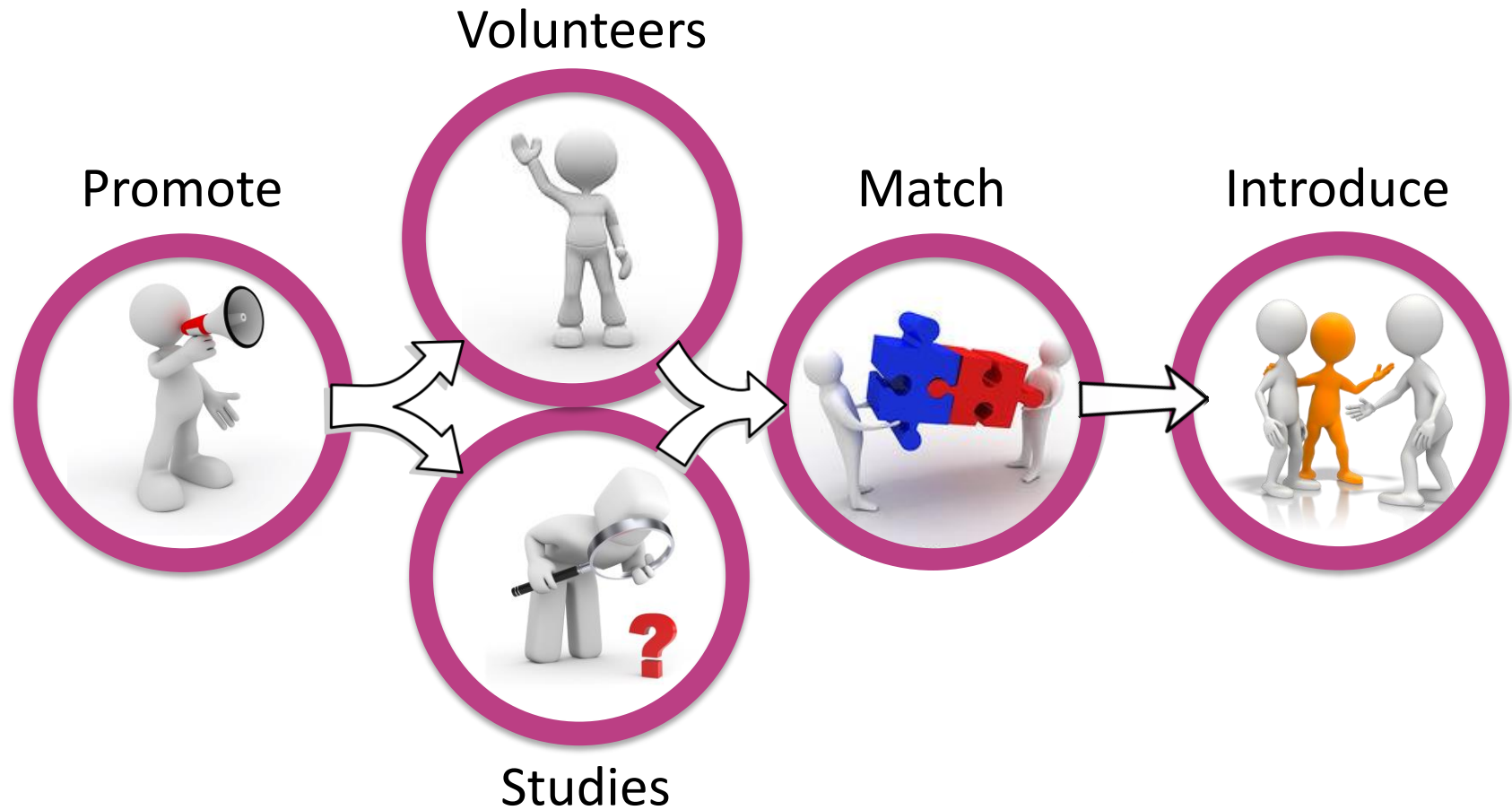
# Working with people affected by dementia & 3<sup>rd</sup> Sector on a new approach





# What is Join Dementia Research?







# Marketing & Promotion



## Social Media

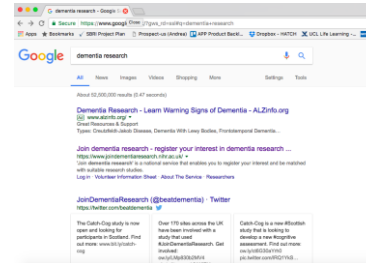


## News



**BBC NEWS**

## Search



## Clinics



# Registration channels

## Online



## Helpline

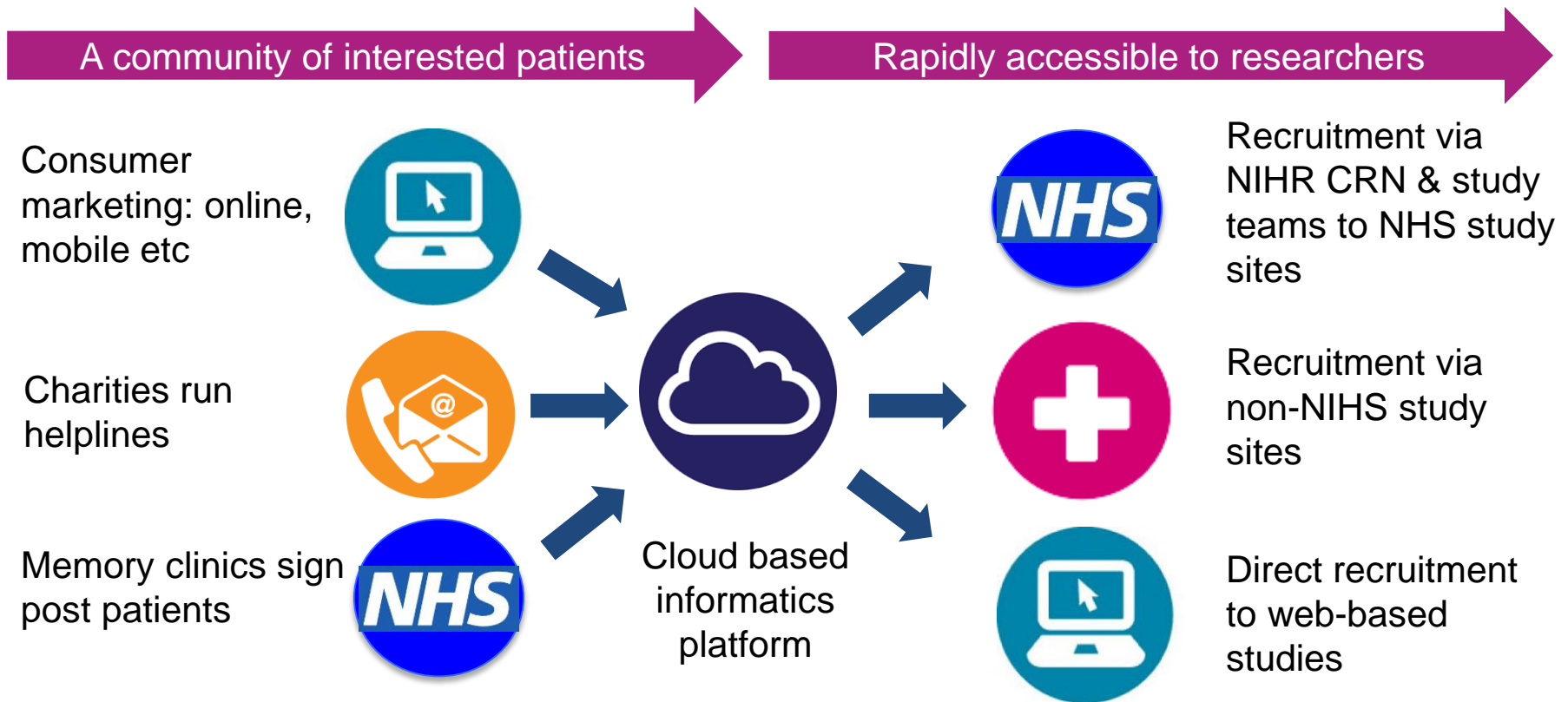


## Post

A form titled 'INFORMATION ABOUT THE VOLUNTEER'. It includes instructions: 'On the next two pages, please enter either: • Your details (if you are signing yourself up as a volunteer) OR • The volunteer's details (if you are signing up someone else)'. Below this, it says 'Before completing this section, please read the declaration text carefully (either A or B) on page 6. You MUST answer ALL the questions on pages 4 and 5.' The form has sections for 'TITLE (Dr, Mr, Mrs etc.)', 'VOLUNTEER'S FIRST NAME', 'VOLUNTEER'S SURNAME', 'DOB (DDMMYYYY)', and 'Is the volunteer registering as someone who has a diagnosis or is being investigated for a dementia related disorder?'. It also has a section for 'If yes, what is the volunteer's diagnosis?' with options: 'ALZHEIMER'S DISEASE', 'VASCULAR DEMENTIA', and 'MILD COGNITIVE IMPAIRMENT'. There is a large '21' in a box. At the bottom, there is a section for 'ANY OTHER DISABILITIES (please specify)' and a small '4' in a red box.

[www.JoinDementiaResearch.org.uk](http://www.JoinDementiaResearch.org.uk)

# Operating model:



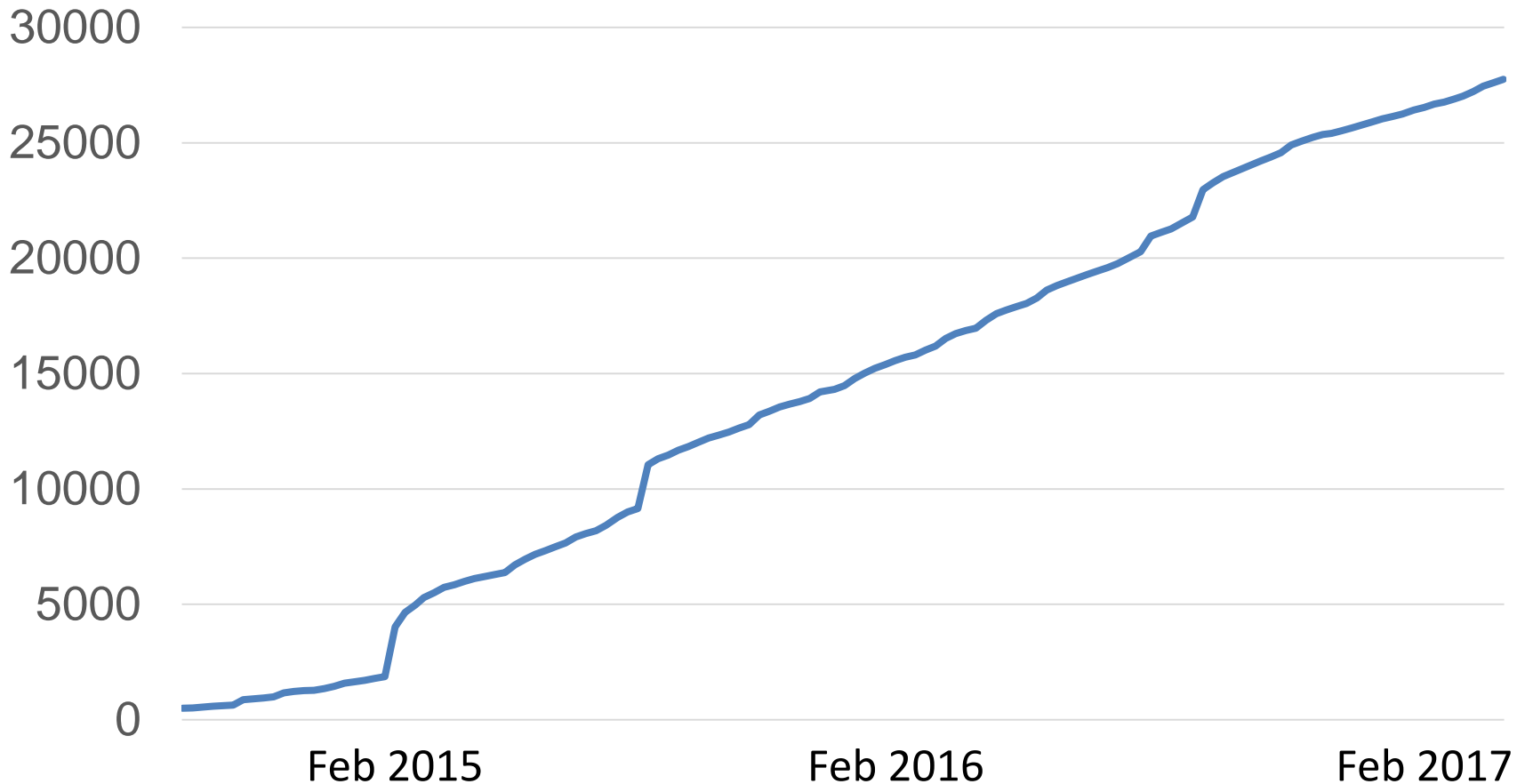
***Coming Together is a Beginning.  
Keeping Together is Progress.  
Working Together is Success.***  
**-Henry Ford**



**Where have  
we got to?**

# Growth of dementia research

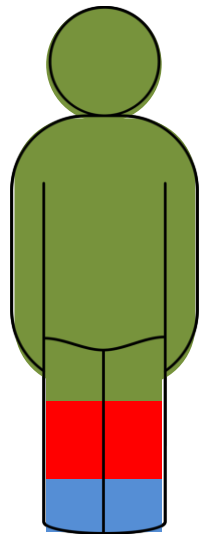
## Volunteers Registering on JDR



# Volunteer experience



has **increased my awareness** of what research is going on...



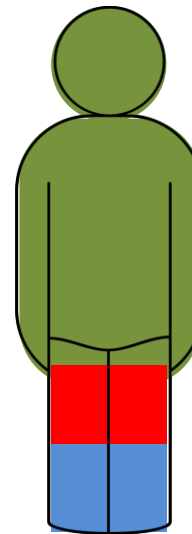
**75% Yes**

**15% No**

**10% Don't know**



has **made it easier** to take part in dementia research...



**66% Yes**

**16% No**

**18% Don't know**



# Research use



**806**

trained researchers  
using the service



**171**

NHS, University & commercial sites  
have used the system



**28,465**

total volunteers



**151**

Studies have recruited



**26%**

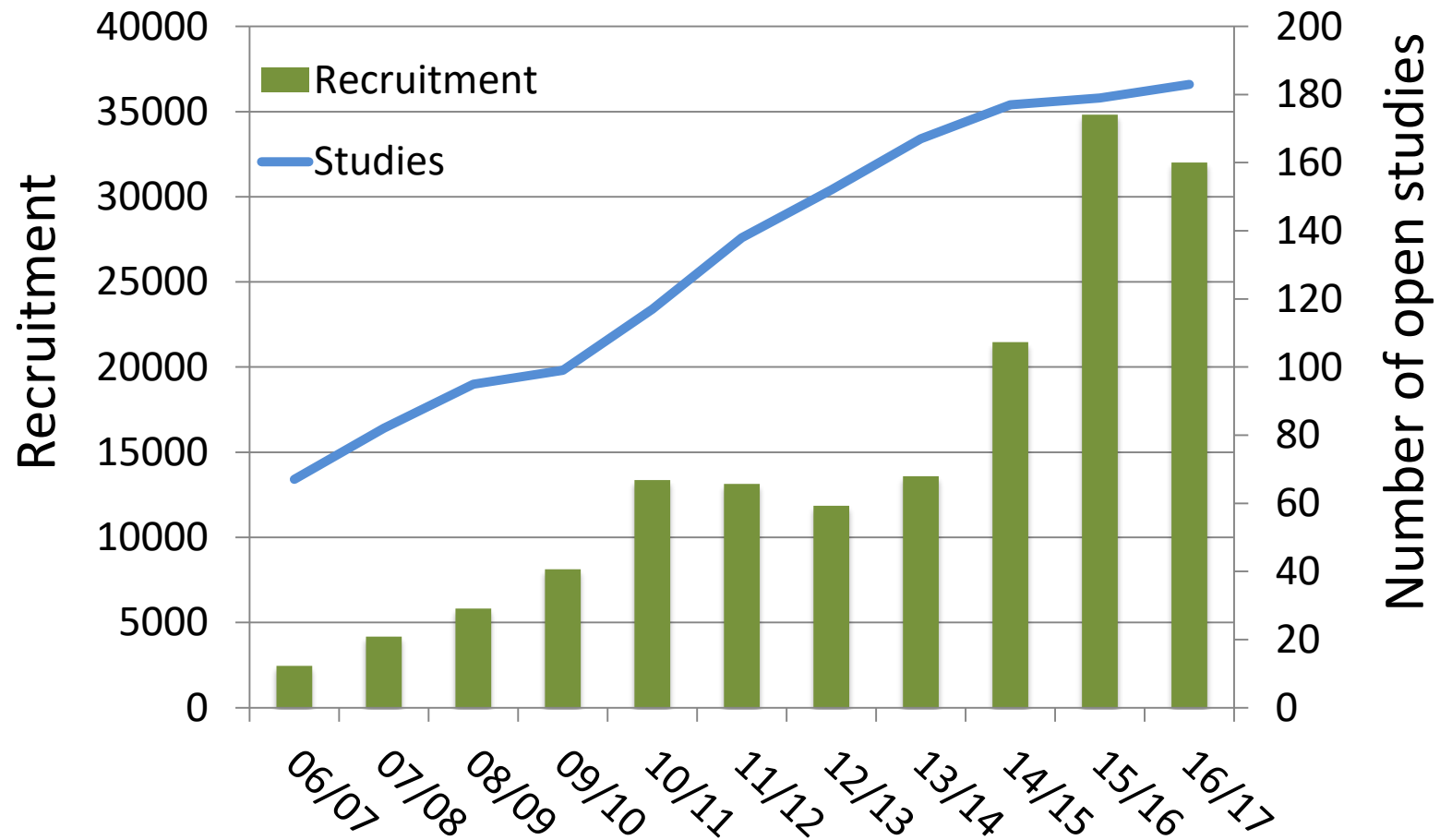
of volunteers have  
participated in a study



**7,502**

participants that have enrolled  
in studies to date

# Growth in UK dementia research 2006 - 2017











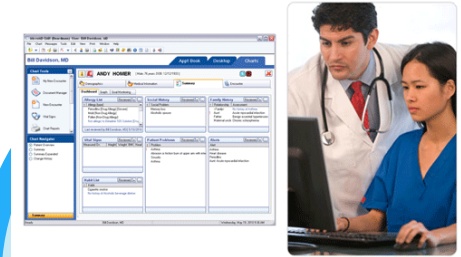
“Every newly diagnosed person with dementia and their carer receiving information on what research opportunities are available and how they can access these through **Join Dementia Research.**”



**What's next?**

# Development of v2

Better user experience  
More registrations  
Better data



Links to Electronic  
Medical Records  
2%  $\Rightarrow$  50%

## JDR v2

Generalizable & scalable  
Dynamic data collection  
Intelligent study matching

New cloud-based platform

Better user experience  
More powerful screening  
Faster, cheaper & more accurate



Links to registries &  
other research  
initiatives



Supports multi-  
channel consumer  
applications



Helpdesk  
functionality &  
widgets



Dementia

UK

International

### UK dementia value realisation

- Increase JDR share of recruitment
- Grow size of JDR NHS network
- Develop value-added services

Year 1 - 3

### International dementia expansion

- Develop & deliver 'JDR' in European & other international markets
- Globalise 'JDR'

Year 1 - 5

Other diseases

### UK market development

- Develop and deliver registers in other diseases
- Grow the JR Ltd network through the NHS

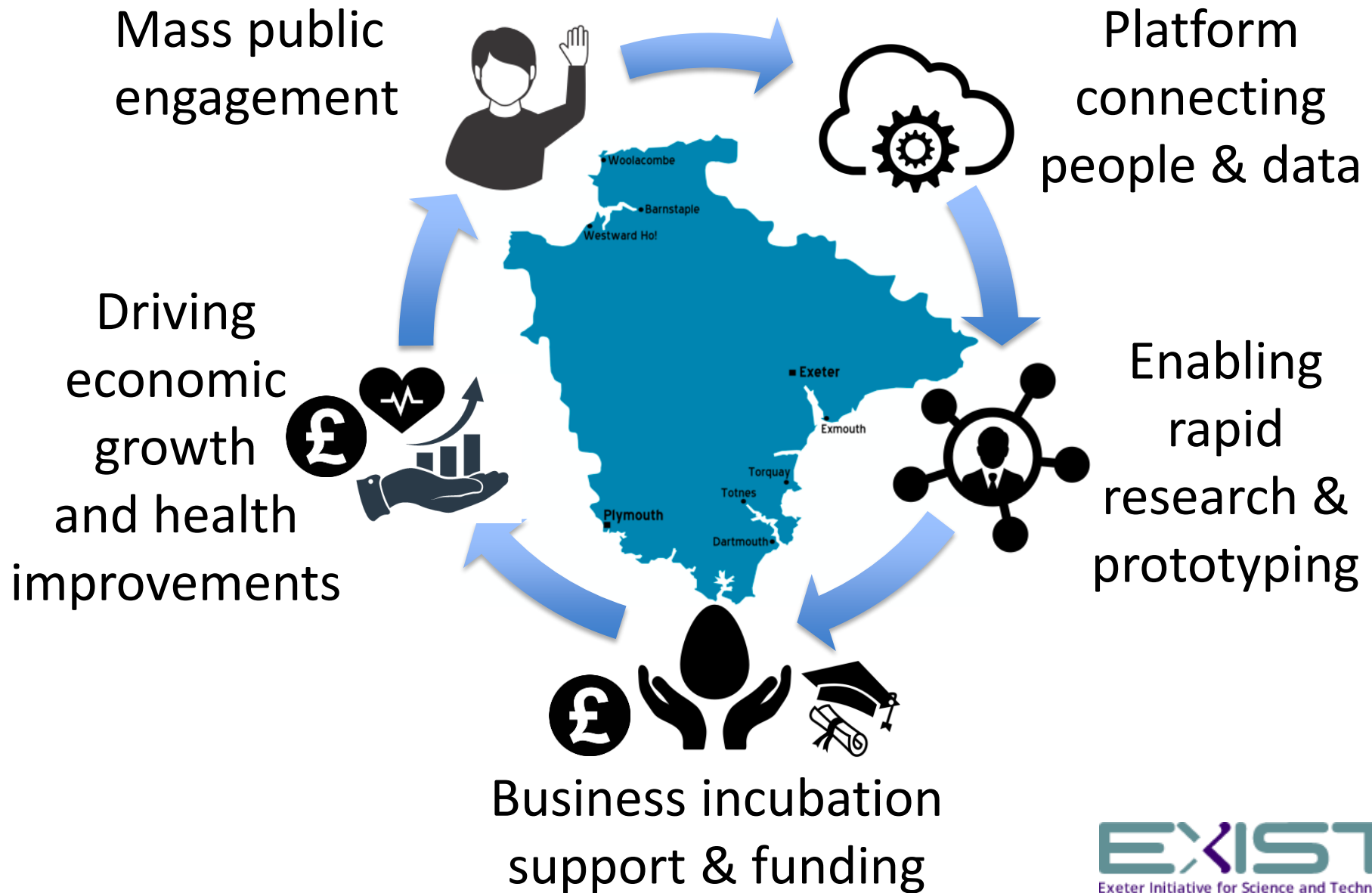
Year 2 - 5

### International diversification

- Develop and deliver register in other disease areas in international markets
- Globalise disease specific registers

Year 3 - 5

# Devon leading the world in health innovation



# Thank you!



Let's Talk

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