

Working Together: Training and Development Programme **2018**

For healthcare professionals, researchers,
patients, carers and the public

Approaches & Techniques Workshop

April 30th 2018



**WORKING
TOGETHER**

Patient and Public Involvement
in the Thames Valley

Today is a collaboration....



Collaboration for Leadership in
Applied Health Research and Care
Oxford

**NIHR Clinical Research
Network Thames Valley
and South Midlands**

Oxford 
Academic Health
Science Network


**National Institute for
Health Research**

Housekeeping



- **Take a break**
- **Fire**
- **Amenities**
- **Photos**
- **WiFi**

Twitter #ppitv

Format for today

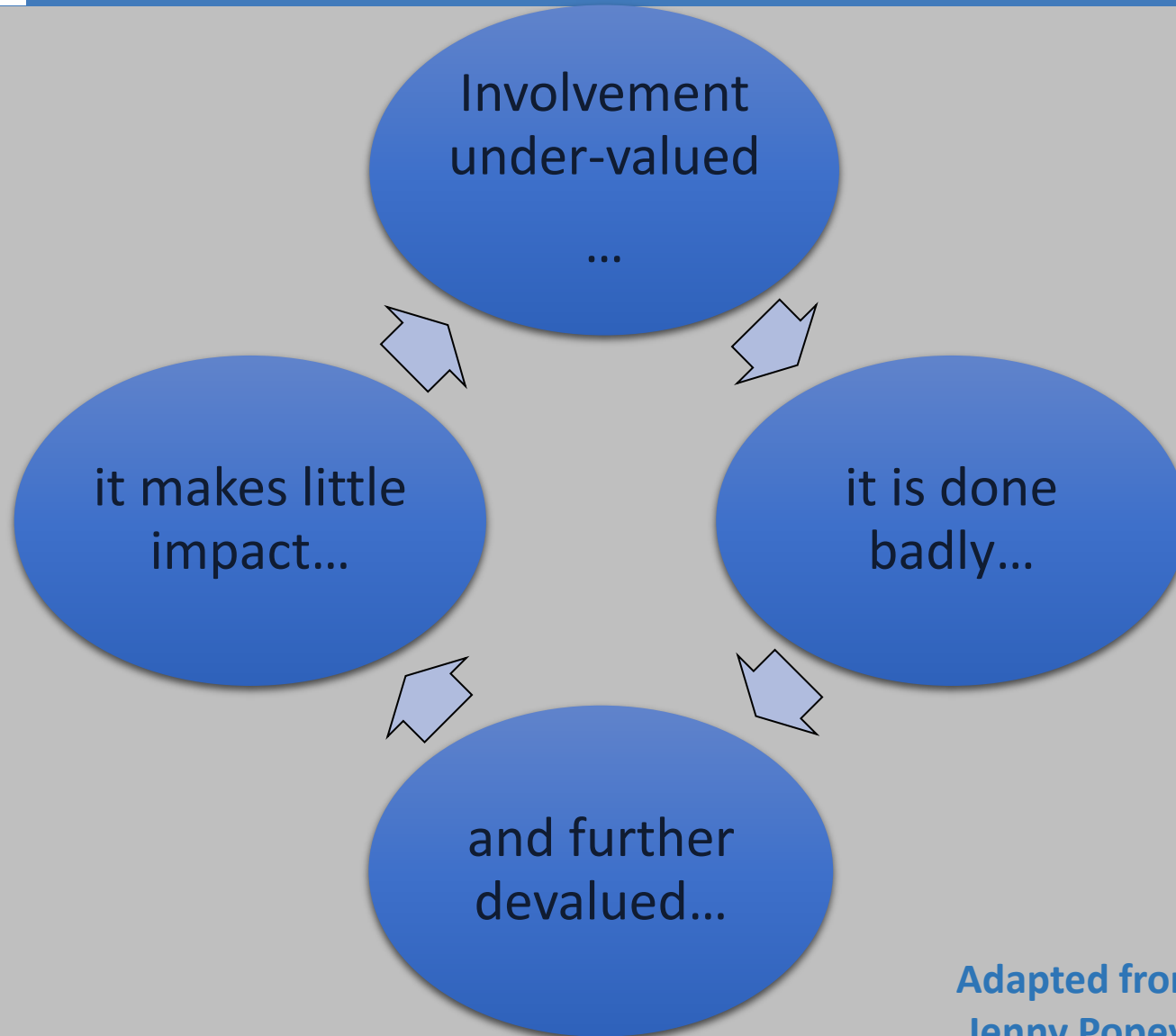


- **Intro and a talk**
- **Questions**
- **LUNCH – 13.00 – sign-up to workshops**
- **2 more talks**
- **Workshops**
- **Summing up**

Who is in the room?



- **14 lay partners**
- **7 researchers**
- **9 clinicians/managers**



Adapted from
Jenny Popey

Working Together: Training and Development Programme | 2018

For healthcare professionals, researchers, patients, carers and the public

Increasing awareness using social media

April 30th 2018



Oliver Evans

Engagement and Communications Lead

NIHR Clinical Research Network Thames Valley and South Midlands



**WORKING
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Patient and Public Involvement
in the Thames Valley



Donald J. Trump ✓

@realDonaldTrump

 Follow

Everyone knows I am right that Robert Pattinson should dump Kristen Stewart. In a couple of years, he will thank me. Be smart, Robert.

4:48 PM - 22 Oct 2012

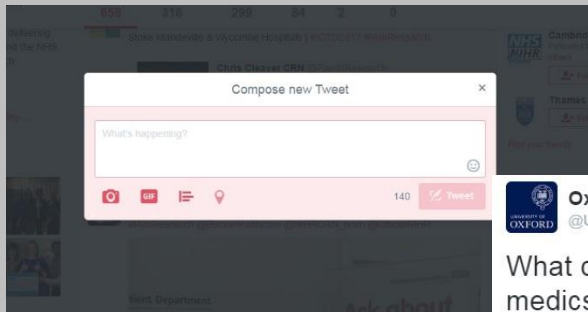
  54,636  60,190

What is social media?



- Writing messages that appear on the internet for the world to see
- Can be text, photo and video and have links to websites
- People set up a 'profile' which others can see and follow, so they see that person's messages in future

Twitter:



Oxford University @UniofOxford Following

What can human factors research teach medics about improving healthcare?
po.st/ki5Nt2

“People resist human factors when they think you're trying to make them a better human. You're trying to make the interface better, not the people.”


Dr Lauren Morgan
Human factors researcher
Kadoorie Centre
Nuffield Department of Surgical Sciences



#OxSciBlog

FMRIB (Oxford Uni) @FMRIB · 5m
Biased visceral perception through fear learning Biased intensity judgements of visceral sensations after learning... [dvr.it/PDNQwr](https://doi.org/10.1093/dvr/it/PDNQwr)


Oxford Martin School @oxmartinschool · 10m
Join us tomorrow at 5pm for @DomDPJohnson on 'The ecology of war', or watch live on YouTube or FB: ow.ly/Rj5a30bZQa8 #natureconflict



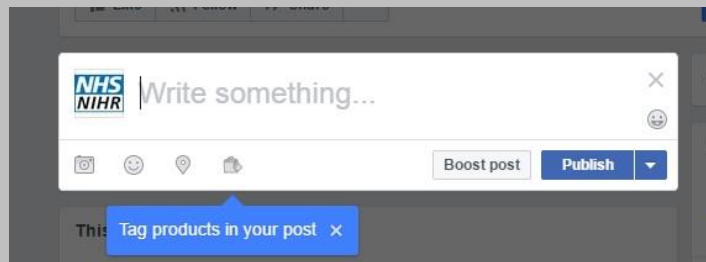
'The ecology of war: an evolutionary perspective on conflict over re...
Competition over resources and territory is not just a feature of modern or historical times, but a recurrent theme in the natural world, and a phe...
oxfordmartin.ox.ac.uk

NIHR CRN Eastern Retweeted

John@Vasculitis UK @vascuk · 13m
Busy at the @vascuk stand #Vasculitis & U #NHSresearch day @NNUH w/ with #iamresearch #whywedoresearch




Facebook:



Posts

NHS NIHR NIHR Clinical Research Network: Thames Valley and South Midlands
18 hrs · 🌐

People like Monique are making research happen in the NHS, read her story here <https://www.nihr.ac.uk/.../being-part-of-such-a-vast-pro.../5387>



61 people reached Boost post

👍 Like 💬 Comment ➦ Share

👤 Sue Duncombe and Shaney Jewell

NHS NIHR Write a comment...
Press Enter to post.

NHS NIHR NIHR Clinical Research Network: Thames Valley and South Midlands
Yesterday at 10:59 · 🌐

Listen to Bob's story of how he took part in NHS research @BucksHealthcare after three heart attacks. 1h22m06s

Others:



- Youtube – video
- Instagram – photos
- LinkedIn – business
- Tumblr - blogs

What for?



NIHR CRN TVSM @NIHRCRN_tvsm · Feb 13

Join the Oxford BioBank and support research into conditions such as diabetes, heart disease and obesity. Visit oxfordbiobank.org.uk for details

Join the Oxford BioBank and support research into conditions such as diabetes, heart disease and obesity.

If you are healthy and aged between 30-50, please contact us.

01865 857284 / obb@ocdem.ox.ac.uk / oxfordbiobank.org.uk

NIHR CRN TVSM @NIHRCRN_tvsm · 20h

The world's first human testing of a vaccine to protect over 65-year-olds against influenza has begun in the NHS tinyurl.com/y7ja6osh

The world's first widespread human testing of a flu vaccine which researchers hope will protect more over 65-year-olds has begun in the NHS.

NIHR CRN TVSM @NIHRCRN_tvsm · Feb 14

Alun recommends talking to your doctor about NHS research or visiting ukctg.nihr.ac.uk to find trials

"I would definitely encourage anyone to ask about taking part in research when they see their GP or consultant. Even if you don't benefit yourself, participation offers an unusual way of contributing to the wider community."

- Alun, who took part in Parkinson's research

Ask your doctor about research or view opportunities at ukctg.nihr.ac.uk

awareness

Why?



- Reach a massive audience – 330m on Twitter, 2bn Facebook
- It is how many consume information about the world – through their smartphones
 - Collects peoples' different interests, giving researchers an opportunity to reach a captive audience
 - It's free!
 - Strong options to tell stories – videos, photos, text
- Interactive – people can leave comments / share

Before you begin check....



- With your organisation's communications / media department whether you need permission to set up a social media account for work.
 - If you want to use social media to promote a study, check whether you require ethics approval
- Ask – will I be able to post frequently enough? i.e. at least 3 to 4 times a week

Golden rule:



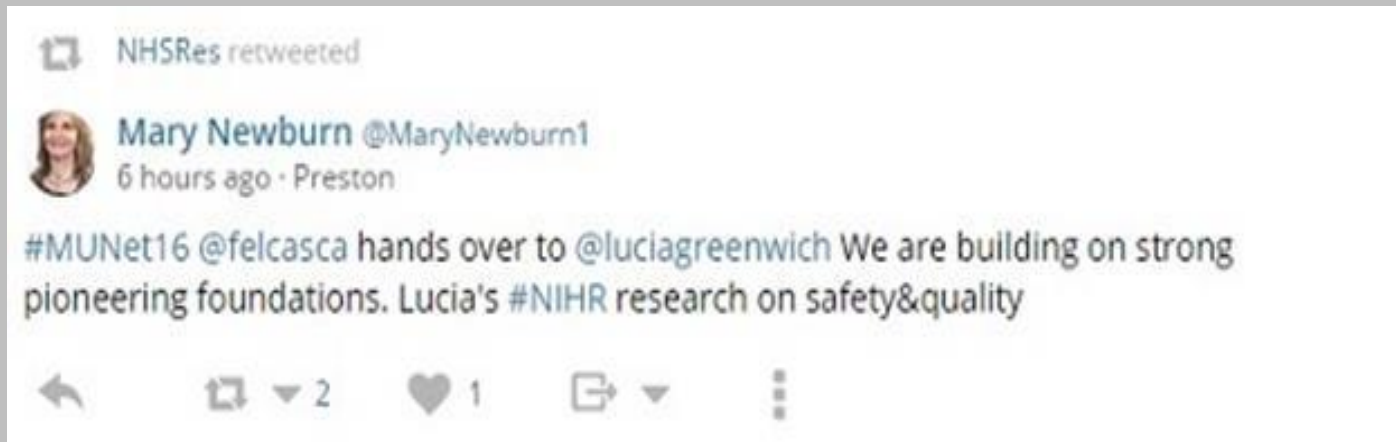
Only publish content worth publishing – too much uninteresting content will lose followers



Use **simple language**, avoiding jargon:



Must have **context** to be understood when read completely “cold”, not like this:



But like this!



NIHR Oxford BRC @OxfordBRC - Feb 22

Science gender equality programme has had positive impact in Oxford, research supported by Oxford BRC finds
tinyurl.com/hpmsgays



4



2

Tell the story in the posting itself



NHS NIHR NIHR Oxford BRC @OxfordBRC · 12 Sep 2016

We're proud to have funded the world's first robot-assisted in-eye operation with @UniofOxford

 **Robot operates inside eye - BBC News**

Surgeons in Oxford have used a robot to operate inside the eye - in a world first. A team at Oxford's John Radcliffe Hospital used the device, controlled via...
[youtube.com](https://www.youtube.com)

Retweets: 3 Likes: 2

Give a **shortened link** – even if most won't follow it



Every post must have a **photo**



Text-led photos / graphics are even better



NHS NIHR NIHR Oxford BRC @OxfordBRC · Jul 17
Keep in touch with Oxford NHS / @UniofOxford research news with Oxford BRC on Facebook! tinyurl.com/jsnvtvg



3

NHS NIHR NIHR Clinical Research Network Thames Valley and South Midlands
31 October at 18:39 · 🌐

Rabinder is taking part in NHS diabetes research to help others. Ask your doctor how you can help research or visit ukctg.nihr.ac.uk



NHS
National Institute for Health Research

"It's really important to take part in research because it can indirectly help you as an individual and, most importantly, you are making a contribution to research where thousands of other people can benefit."

- Newport Pagnell's Rabinder Dawett on taking part in NHS diabetes research

See our website nihr.ac.uk/thamesvalley
For details of studies seeking volunteers visit ukctg.nihr.ac.uk

30 people reached [Boost Post](#)

Like Comment Share

Videos always popular



 **NIHR CRN TVSM** @NIHRCRN_tvsm · Feb 5

Watch: Stephen shares his experience of living with schizophrenia and why he is taking part in NHS mental health research at @BHFT. Read more at nhr.ac.uk/mental-health



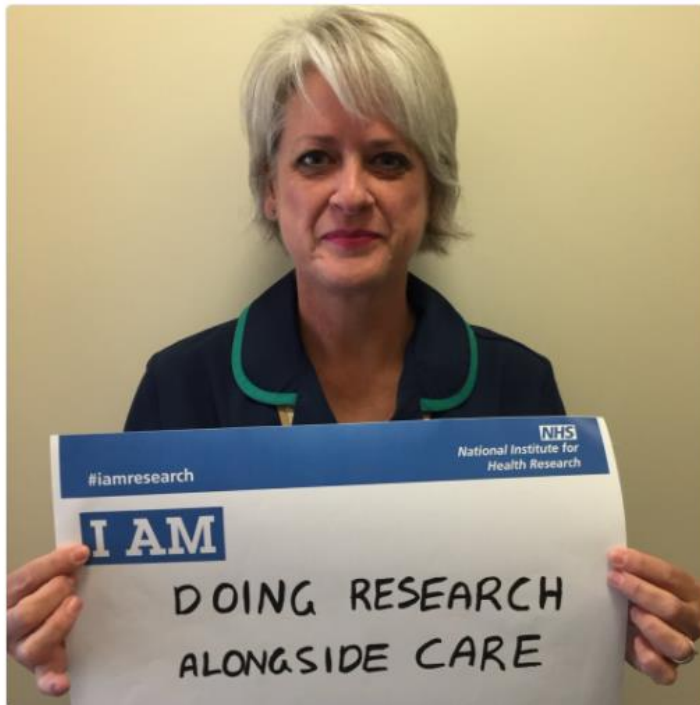
1:53 157 views

🗨️ ↻ 3 ❤️ 📺

Personalise!



NIHR CRN: TVSM @NIHRCRN_tvsm · May 19
Kayleen, Oxford Haemophilia and Thrombosis Centre, Churchill Hospital, on why NHS research matters tinyurl.com/lbn2yu7 #iamresearch

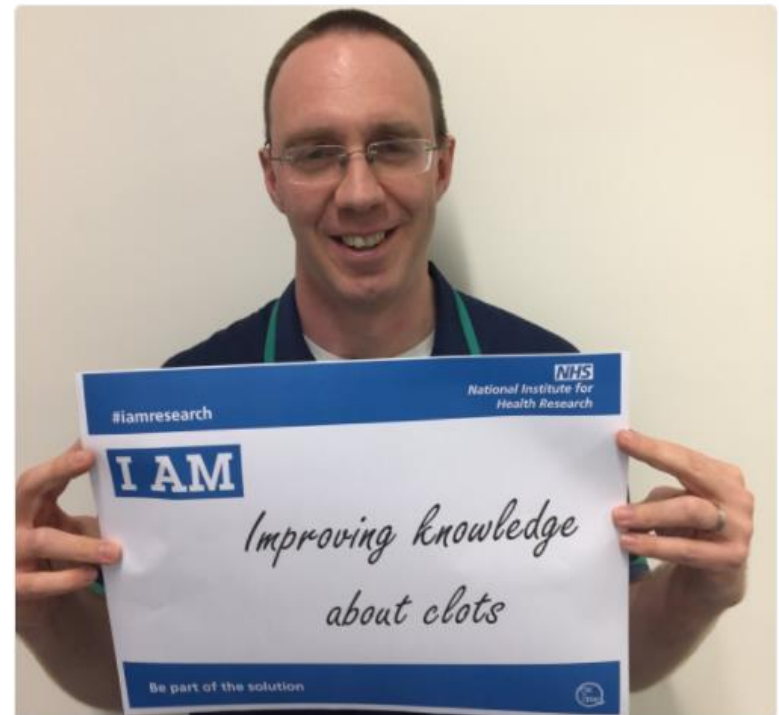


4 retweets 3 likes

You Retweeted



NIHR CRN: TVSM @NIHRCRN_tvsm · May 19
Chris, Oxford Haemophilia and Thrombosis Centre, Churchill Hospital, on why NHS research matters tinyurl.com/lbn2yu7 #iamresearch



1 retweet 3 likes

You Retweeted

Personalise!



NIHR CRN: TVSM @NIHRCRN_tvsm · May 20

Lizzy, Emma and Iona from @UniofOxford Clinical BioManufacturing Facility on why NHS research matters tinyurl.com/lbn2yu7 #iamresearch



NIHR CRN: TVSM @NIHRCRN_tvsm · May 19

Be creative!

Niki Retweeted



Este Haim @jizziemcguire · 4 May 2016

the met ball inspired me to start wearing my insulin pump on my boot,
@nickjonas you approve?



78 401 2.3K

Niki Retweeted

Beyond Type 1 @BeyondType1 · May 17

Aim for **high quality photos**



NIHR Oxford BRC @OxfordBRC · 24 Jun 2016

Video & podcast of our debate on challenges & opportunities of big data in medical research tinyurl.com/zozg7hv



Makes all the difference



NIHR Oxford BRC @OxfordBRC · 24 Jun 2016

Video & podcast of our debate on challenges & opportunities of big data in medical research tinyurl.com/zozg7hv



NIHR Oxford BRC @OxfordBRC · 26 Nov 2013

@AshmoleanUEP fantastic venue for tonight's seeing the human heart event



DO:



Interact – keep an eye on comments and mentions and respond quickly

Use **#hashtags** sparingly and only for genuine, on-going campaigns / events that others will write about.

Post often – but not too often!

Share others' posts – but don't over-do it

Follow relevant people – they could follow you

DON'T:



- **Opinions:** be careful commenting on politically sensitive issues outside of findings e.g. fair funding.
- **Tone:** don't be flippant, rude, derogatory – don't get into fights
- **Repeated messaging:** don't repeat the same post again and again in close proximity. Find a new, interesting way to repeat it.

Advertising on

facebook



Advertising on Facebook:

- Liking / befriending someone on Facebook and following does not mean you will see everything they post.
- What you see is what Facebook thinks you want to see determined using an algorithm based on your use of Facebook.

So you may well get ignored



Advertising on Facebook can overcome this:


- Users pay Facebook to add adverts into the newsfeed of a selected group e.g. women aged 18-24 in Oxford.
- Users can choose to close the advertisement or simply ignore it.
- Can be cost effective with the right study for the right people – but not all e.g older generations


 You are targeting men and women ages 18-40 who live in **2 locations**.

Location:
United Kingdom: Oxford, Oxfordshire (OX3 7), Latitude 51.76 Longitude -1.25 Oxford, Oxfordshire (+31 km) England

Age:
18-40

[Hide full summary](#)

 This promotion will run for **7 days**.

 Your total budget for this promotion is **£20.00**.

4,055 People Reached [?]	81 Clicks [?]	£20.00 Total Spend [?]
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Working Together: Training and Development Programme | 2018

For healthcare professionals, researchers, patients, carers and the public

Identifying and planning to reach target audiences

April 30th 2018

Lynne Maddocks, PPI Coordinator

NIHR Oxford CLAHRC

**Alison Monk, Communications & Engagement Manager,
NIHR Clinical Research Network Thames Valley/South
Midlands**



Who is your target audience?

❖ Certain health condition

❖ Gender

❖ Location

❖ Ethnicity

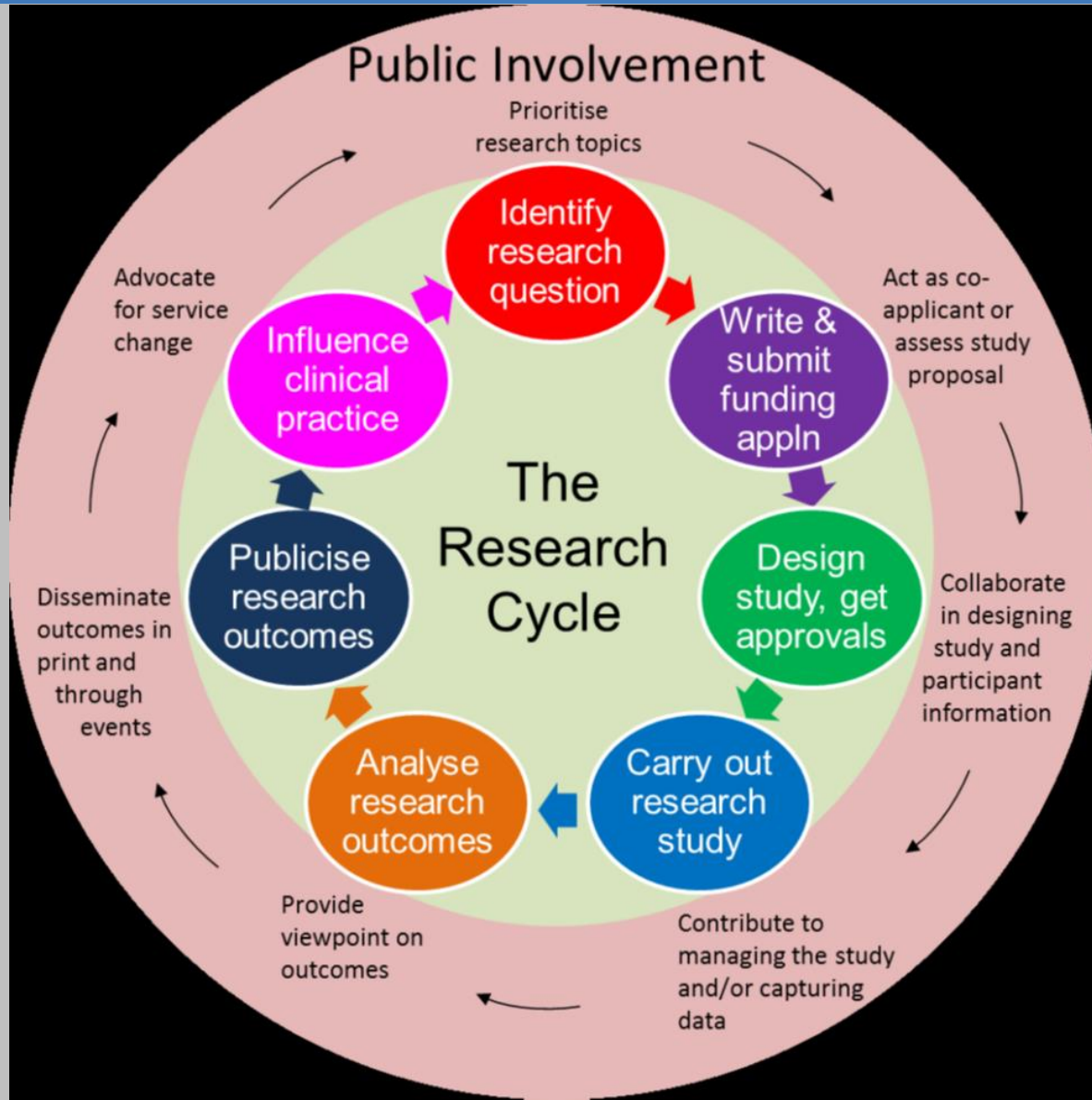
❖ Age



❖ Communities of interest – faith, culture

❖ Something specific to your work

When do you want to contact them?



Why are you seeking their input?



Why/what? = the ask, call to action, message

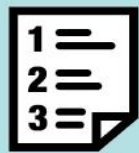


How?

Map relevant
*communities of
interest*



Design
appropriate
*communication
plans*



COMMUNICATION
Strategy

Who? When? Why/what?



Example: Cochrane Tobacco Addiction group



- What questions do **you** think should be researched?
- What priority would **you** give these questions?

Example: Cochrane Tobacco Addiction group



Example: Cochrane Tobacco Addiction group



- UK Centre for Tobacco & Alcohol Studies smokers' panel.
- emailing their own mailing list, which included other stakeholder organisations, such as ASH, the US Food and Drug Administration (FDA) and Public Health England to circulate among their members and/or send out to their mailing lists.
- Sharing the web-link on social media via the Cochrane Tobacco Addiction Group Twitter account (@CochraneTAG)
- doing a Facebook advertisement (specifically designed to target members of the public),
- promoting it at the Society for Research on Nicotine and Tobacco (SRNT) annual international conference (Chicago, USA),
- Writing blog posts promoting the group and highlighting the survey.
- Patients Active in Research local recruitment website
- Partners such as the Oxford CLAHRC's list of volunteers
- existing smokers panels in collaborating Universities
- Clinical colleagues who could help recruit those with chronic conditions.
- People in Research national recruitment website
- Oxford's Daily Info
- Gumtree
- Stroke Association online forum
- British Heart Foundation online forum
- Diabetes UK online forum

Routes



Directories of voluntary sector groups who support people with particular health conditions and diseases.



Contact a Family – for families with disabled children	www.cafamily.org.uk/medical-information/conditions
Patient - trusted medical information and support – NHS Choices	www.patient.co.uk/directory
Self-Help UK – the guide to patient support and self help	www.self-help.org.uk/directory
Shaping our Lives - National network of service users and disabled people	http://www.shapingourlives.org.uk/list-of-members
Rare Disease UK – the national alliance for people with rare diseases and all who support them	http://www.geneticalliance.org.uk/find-support/
McPin Foundation – transforming mental health research	http://mcpin.org/resources/service-user-and-carer-groups/
Coach – County of Oxfordshire advice on care & health set up by GP Federation	http://directory.my-coach.org.uk/#/search/list

Communication plan



- Your objectives, call to action
- Who your target audiences is
- How you will achieve your objectives
- What activities/tools will you use eg social media, talks, leaflets, adverts, consider format
- Your timetable
- How you will measure the results



How will you measure success?



Build into your plan so you can measure you progress



Communication plan



- Be creative and responsive
- Start early-save time later
- Relevant communications plan
- Develop your messages before you communicate

Record where you recruited



This is important as otherwise you will not know which of your communication routes have been most successful

Where did you hear about us?

2 local recruitment routes



<https://patientsactiveinresearch.org.uk>

Patients Active in Research
Thames Valley

Working with patients at all stages of medical research

Home About Us ▾ Info for the Public ▾ Info for Researchers ▾ Current

You are here: Home / Current Involvement Opportunities

Current Involvement Opportunities

Involvement Matters

Patients, carers, professionals and the public working together in the Thames Valley and Milton Keynes.



Edition 14 - 1st February 2018

Opportunities

Women who have recurrent urinary tract infections

This study is looking for four women who could help with PPI support. It is looking at D-Mannose, a sugar

To sign up email
involvementmatters@phc.ox.ac.uk

Working Together: Training and Development Programme **2018**

For healthcare professionals, researchers, patients, carers and the public

Coproduction

April 30th 2018

Sian Rees

Director Patient and public Involvement, Engagement and Experience

Oxford Academic health Science Network



Coproduction: what do we mean?



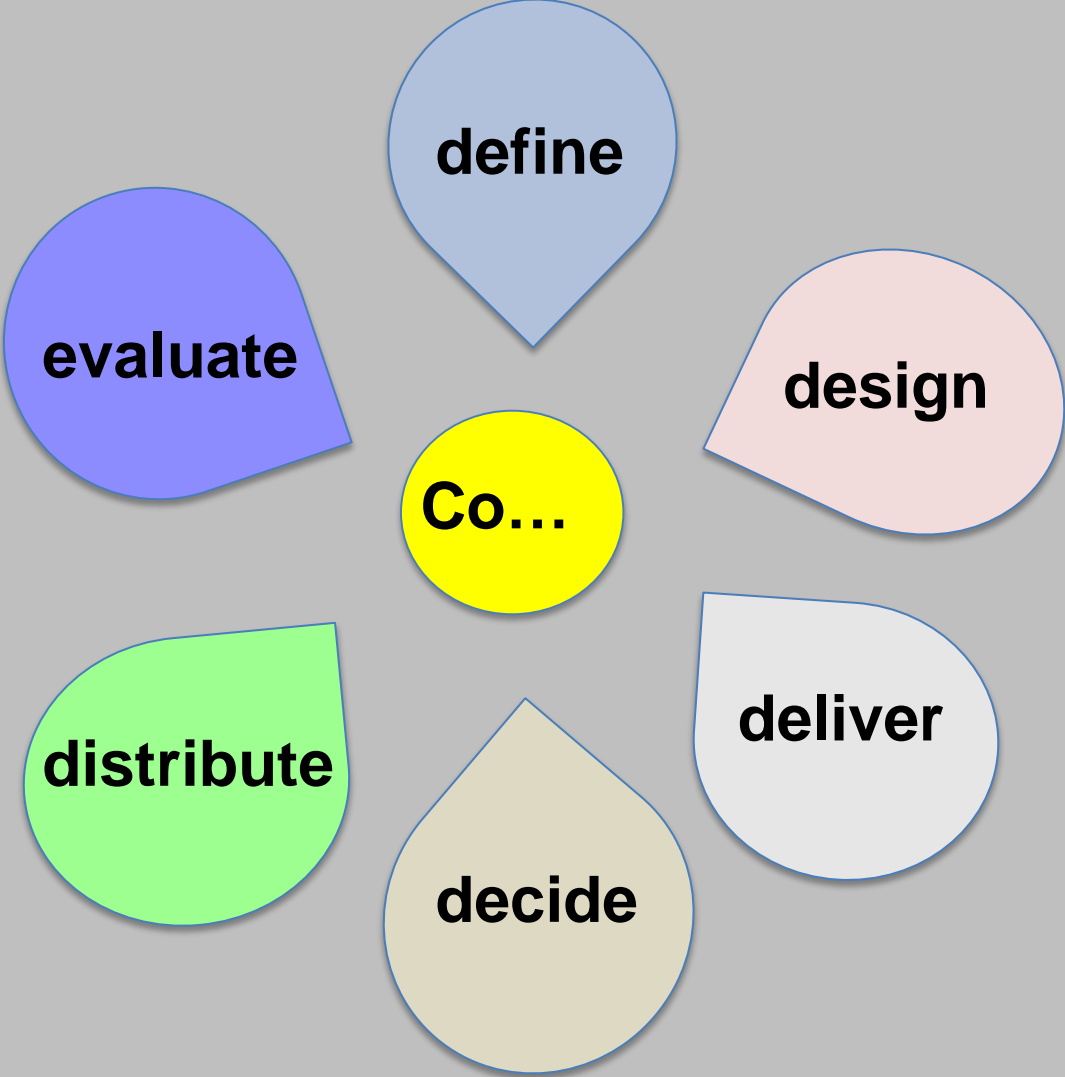
“ A relationship where professionals and citizens share power to plan and deliver support together, recognising that both have vital contributions to make in order to improve quality of life for people and communities. [6] ”

No More Throw Away People

The parable of the blobs & squares



Co-production: the components



5 Ds and an E

Reflection



- **What will you start to do?**
- **What will you stop doing?**
- **What will you continue to do?**