



Patient and public involvement across the network

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What do we mean by patient and public involvement?

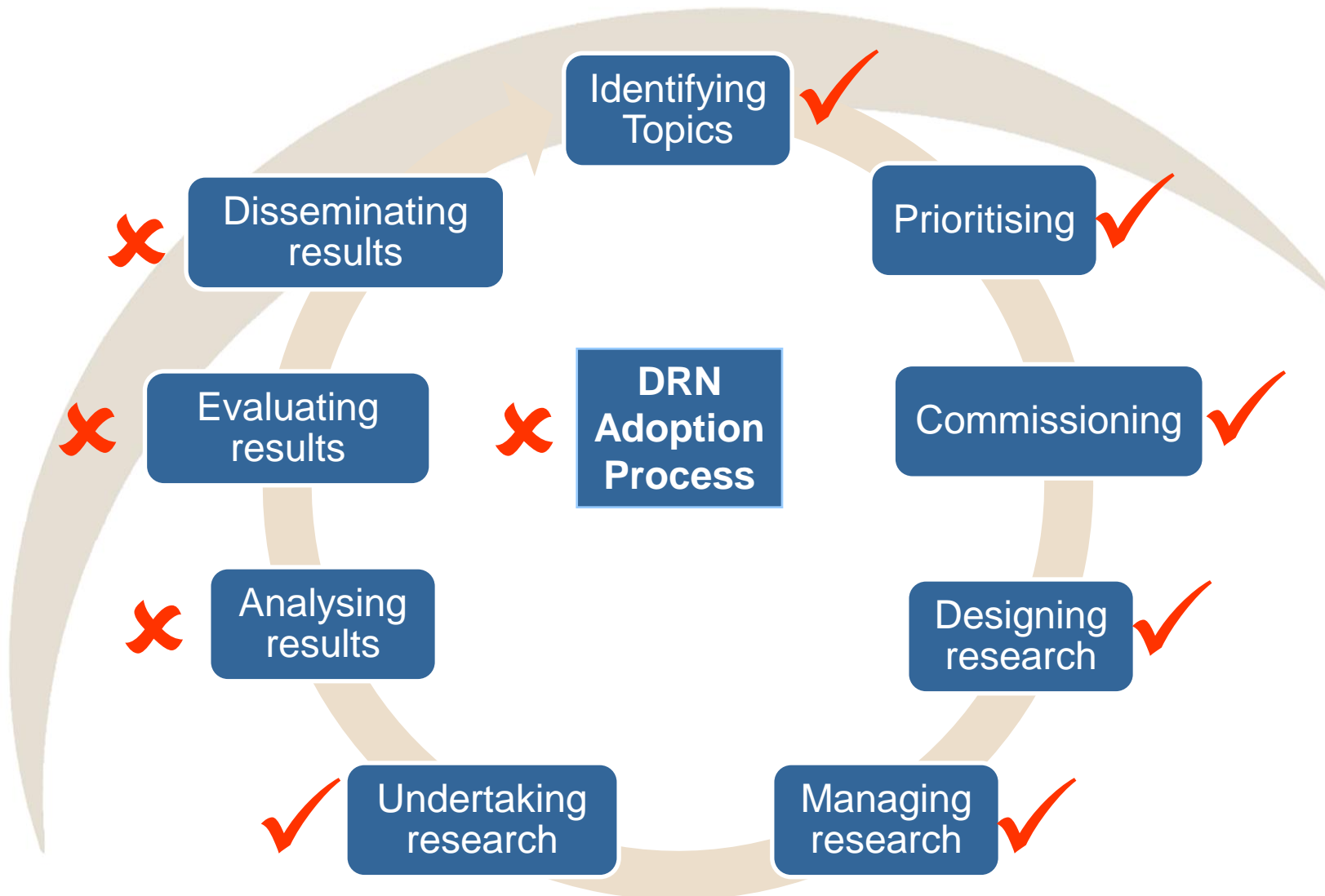


- Not 'participation' in research studies

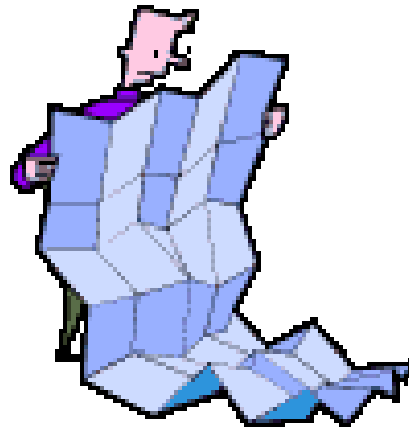
BUT...

- **partnerships** with researchers, clinicians
 - ❑ make research more accessible, more relevant
 - ❑ bring different perspective to researchers'
 - ❑ bring expertise of living with diabetes 24h/day

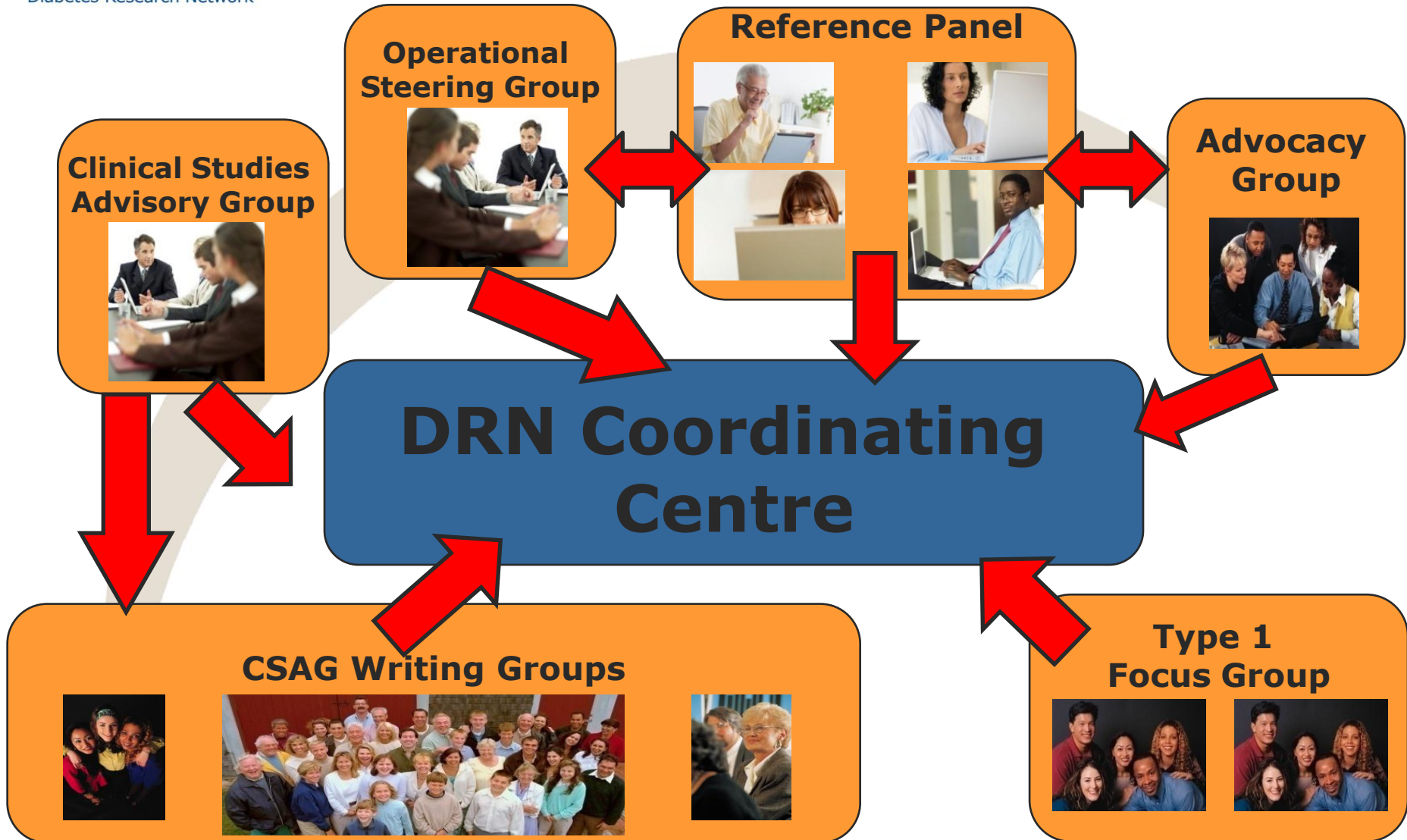
What influence might you have?



What is happening in PPI across the network?



PPI at the Coordinating Centre



Writing Groups

- Neurodegenerative diseases – cognitive impairment
- Telemedicine – new technologies for self-management
- Diabetes and pregnancy
- Neuro-imaging for central nervous metabolic control
- Detection, prevention of complications in young people
- Developing structured education programme
- Prevention of Type 2
- Diabetes in black and minority ethnic populations
- Screening for Type 2 diabetes
- Screening for diabetic retinopathy

NORTH WEST

- Raising awareness – open days, local support groups
- Diabetes & Obesity Res. Network
- Establish an advisory panel

NORTH EAST AND CUMBRIA

- Raising awareness – setting up mobile PPI information kiosk
- Links with Diabetes UK and JDRF groups
- Invitation to join steering group
- Seeking funding for young people's e-forum

SOUTH EAST MIDLANDS

- Raising awareness – university and hospital open days
- Links with Diabetes UK and local DAFNE groups
- Establishing local research forum

EASTERN ENGLAND

- Raising awareness
- Linked to PPIRes (patient and public involvement in research) – a local project in Norfolk
- Establish/link to local forum

NORTH EAST LONDON

- String of awareness raising events
- Lay Advisory Group – links to management group, core executive, multidisciplinary research panel
- Lay panel members advise local researchers on funding applications

NORTH WEST LONDON

- Raising awareness – open days, local events and support groups
- Establishing virtual PPI Group – link with network Advisory Group
- Collaborate on ‘Introduction to Research Handbook’

THAMES VALLEY

- Raising awareness – series of open evenings
- Links to local support groups
- Establish reference panel
- Appoint to Advisory Board

SOUTH WEST & PENINSULA

- Raising awareness
- Series of Type 1 focus groups
- Series of Type 2 focus groups
- Priority setting – top 10 q'naire
- Collaborate to develop protocols from priorities

So...what lies ahead?





Future areas for PPI...

- Developing good, accessible training
- Helping to set research priorities
- Developing patient-originated ideas
- DRN adoption process
- Working with the pharmaceutical industry
- ‘Persuading’ research community – INVOLVE collecting evidence of good PPI

Does PPI really work?

- **OMERACT** – international group Outcome Measurement in Rheumatology Clinical Trials
- Conference in 2002 – on rheumatoid arthritis
- Researchers focused on **pain**
- Patients focused on impact of **fatigue**
- Follow-up research in UK & Sweden **agreed**
- 2006 international consensus to measure fatigue in **all** Rheumatoid Arthritis clinical trials