



Keynote

**ProACT: Designing a Digital Behavioural Change Intervention for
Multi-morbidity Self-Management**

Dr. John Dinsmore



Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

5 key Questions

Q1) Why bother?

Q2) Is it a National/EU/Global priority?

Q3) Is the solution already available?

Q4) Why are you the best person or people to deliver?

Q5) What would happen if you weren't funded? (Would anyone Care?)

Acknowledgements



Dr. Caoimhe Hannigan



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Dr. Mary Galvin



Prof. Anne-Marie Brady

All research participants for their time, commitment and valuable input



Prof. Mary McCarron

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Trinity Centre for Practice and Healthcare Innovation



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**“Develop world-leading
evidence based
innovative research in the
area of digital health”**





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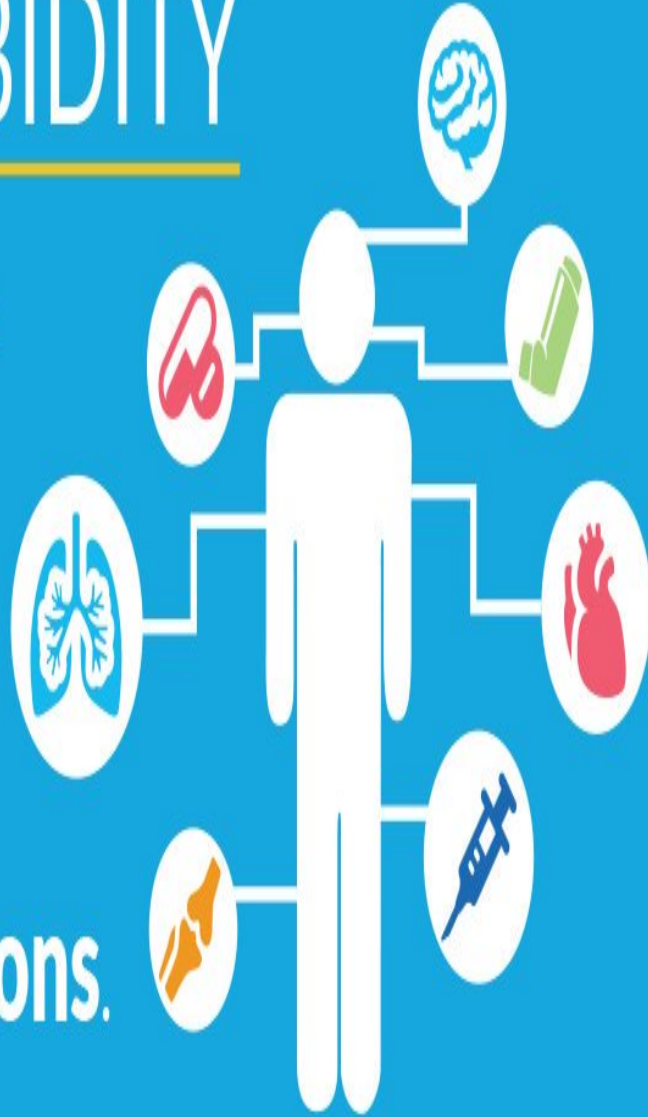
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MULTIMORBIDITY

When **someone**
has **two** or
more
long-term
health conditions.



NICE National Institute for
Health and Care Excellence



Multimorbidity: clinical assessment and management

NICE guideline

Published: 21 September 2016

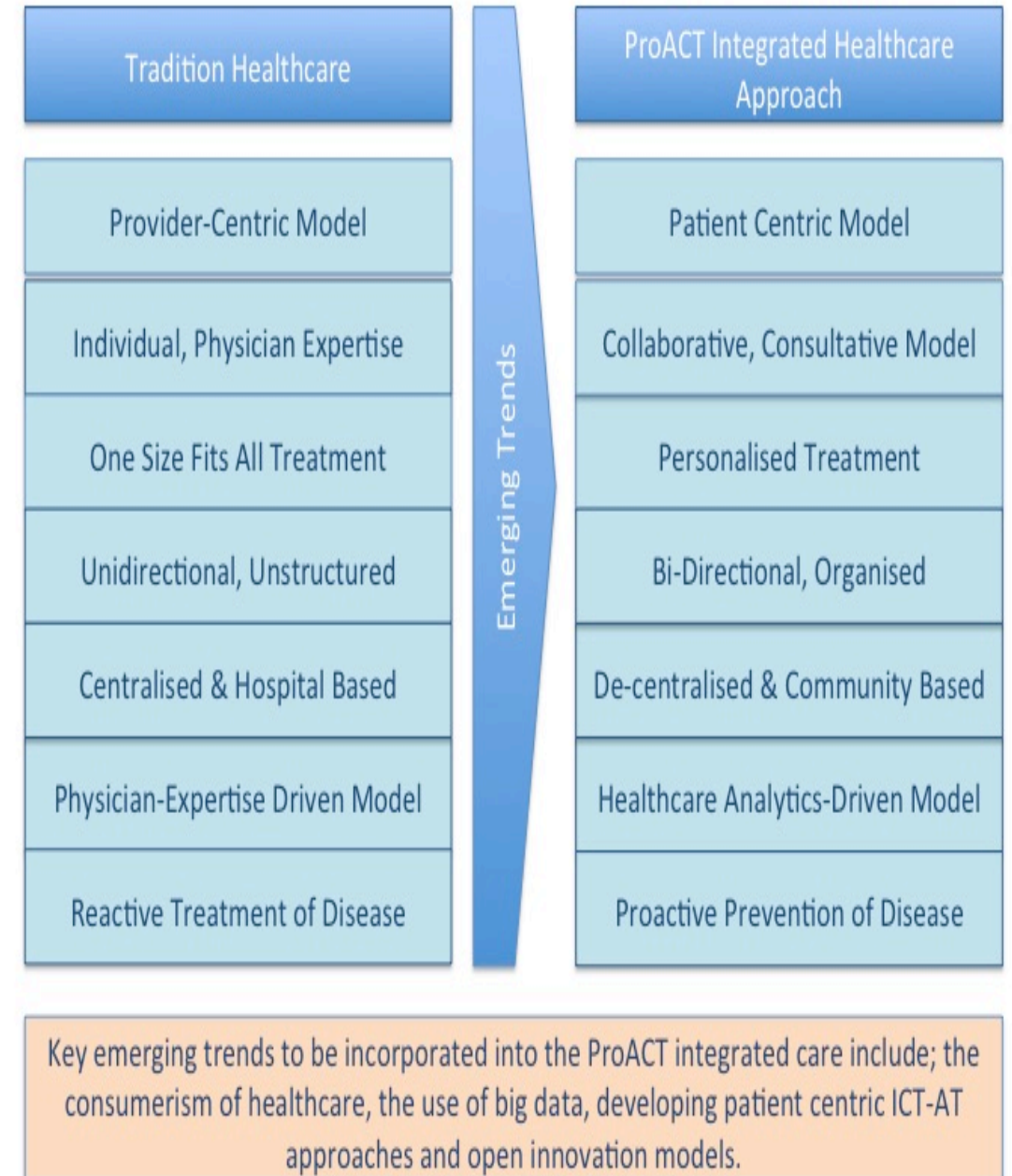
[nice.org.uk/guidance/ng56](https://www.nice.org.uk/guidance/ng56)



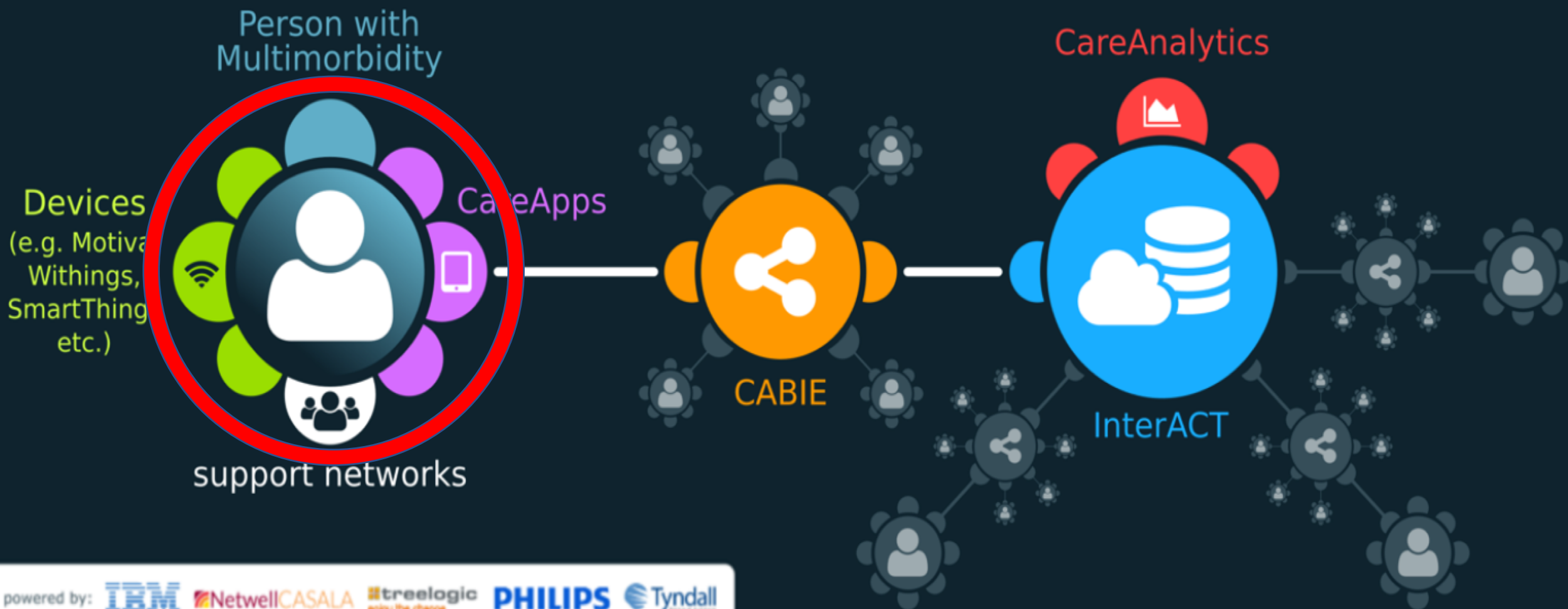
AIMS:

1- Challenge the EU focus on supporting a single disease framework of care to create a patient centric integrated care (IC) ecosystem to understand and manage multimorbidity.

2 - ProACT aims to develop and evaluate a cloud based open API to integrate a variety of new and existing technologies to advance 'home based' integrated care (IC) for multimorbidity self-management.



ProACT ICT-AT Platform



powered by: **IBM** **NetwellCASALA** **treelogic** **PHILIPS** **Tyndall**

built by: **IBM** **NetwellCASALA** **treelogic** **PHILIPS** **Tyndall** **EASPD**

**The people
at the
Heart of
the Issue**



Designing a Digital
Behavioural Change
Intervention for
Multi-morbidity
Self-Management

C.O.P.D.

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

Research Article

Using Action Research and Peer Perspectives to Develop Technology That Facilitates Behavioral Change and Self-Management in COPD

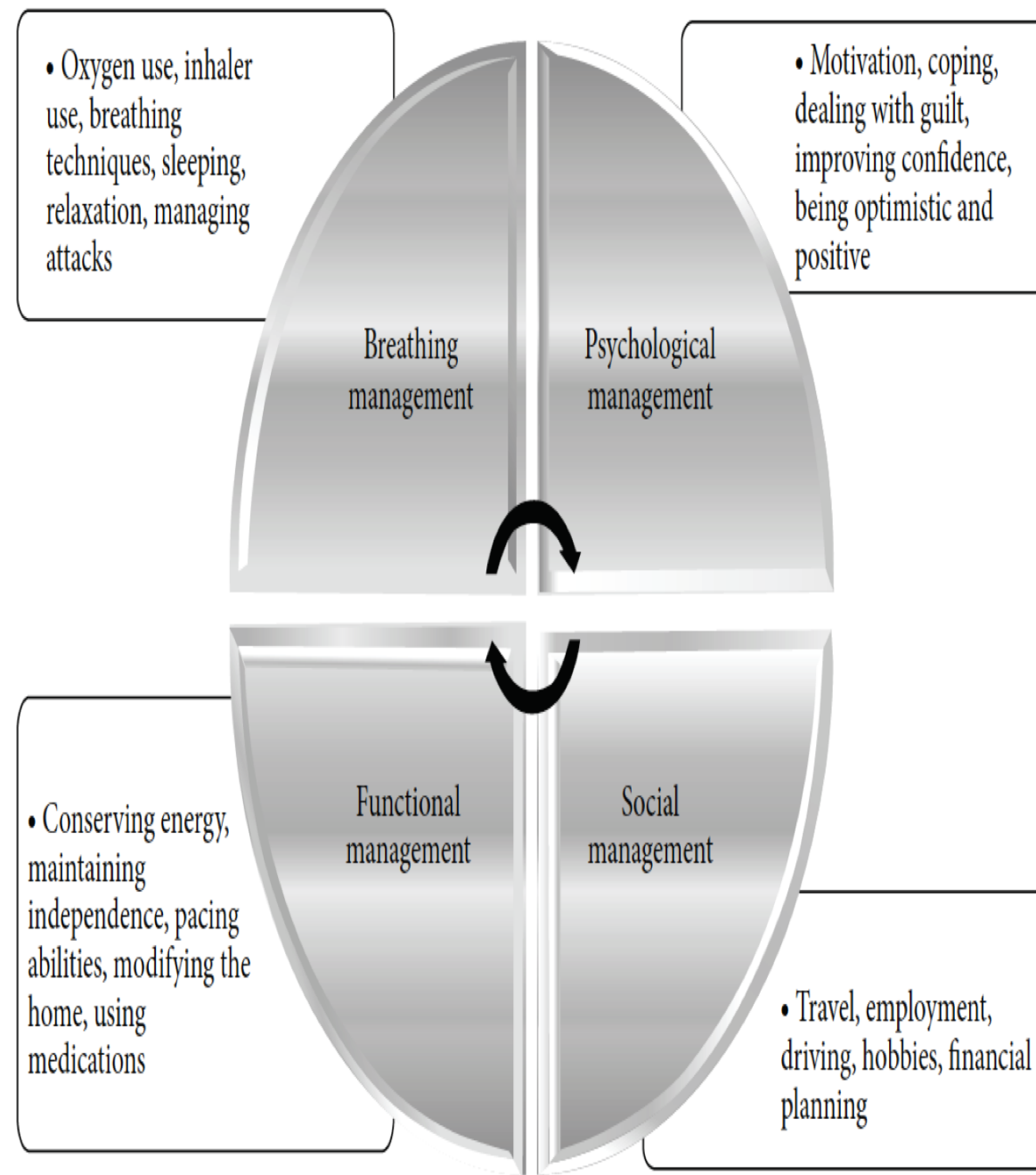
Catherine McCabe,¹ John Dinsmore,¹ Anne Marie Brady,¹ Gabrielle Mckee,¹ Sharon O'Donnell,¹ and David Prendergast²

$n=32$ (53% female)/Average age = 67

12.5% obtained info online

Multi and co-morbidities

- Heart Disease = 16%
- Hypertension = 38%
- Diabetes = 6%
- High cholesterol = 22%
- Anxiety and depression = 31%
- Other 47%

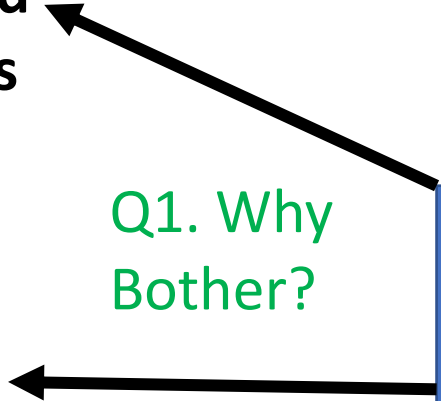


**Combining
science,
politics and
economics**

**The people
at the heart
of the Issue**

Q1. Why
Bother?

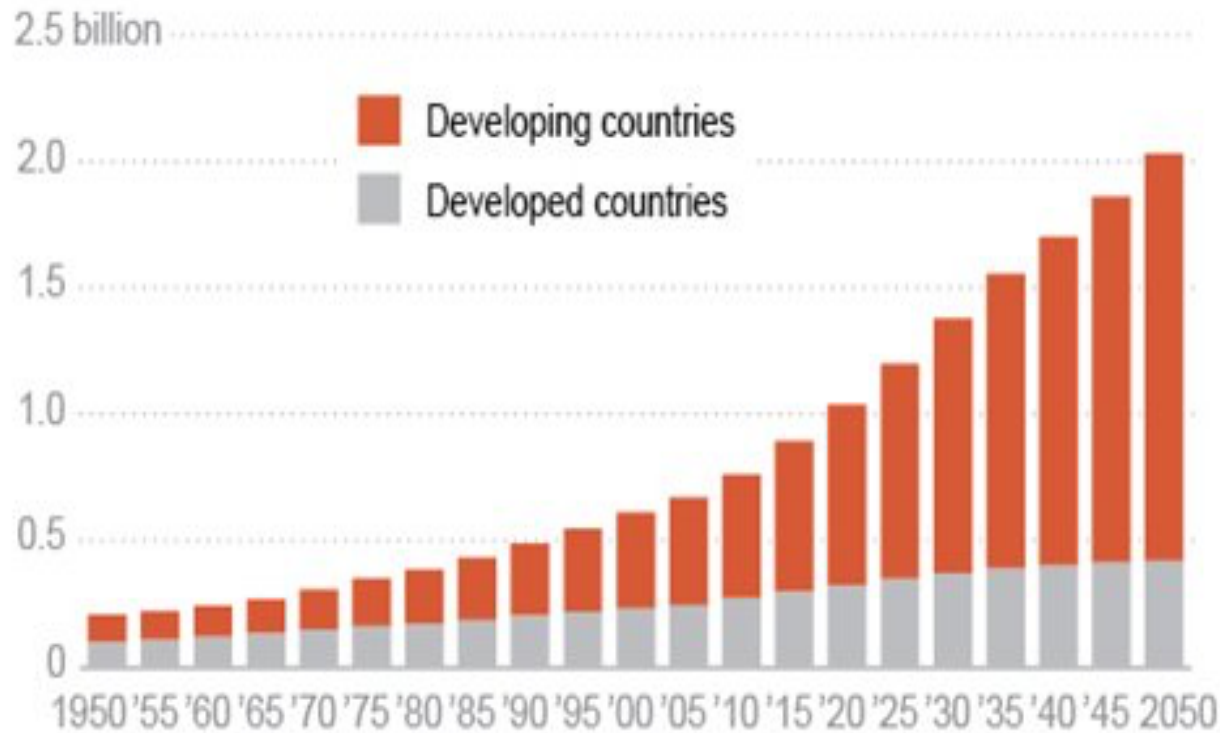
Designing a Digital
Behavioural Change
Intervention for
Multi-morbidity
Self-Management



The Ageing Population

The number of people in the world aged 60 and older is expected to grow past 2 billion by the year 2050.

Total population of people aged 60 and older



SOURCE: United Nations Population Fund

AP

In Ireland...

Number of people aged 65+

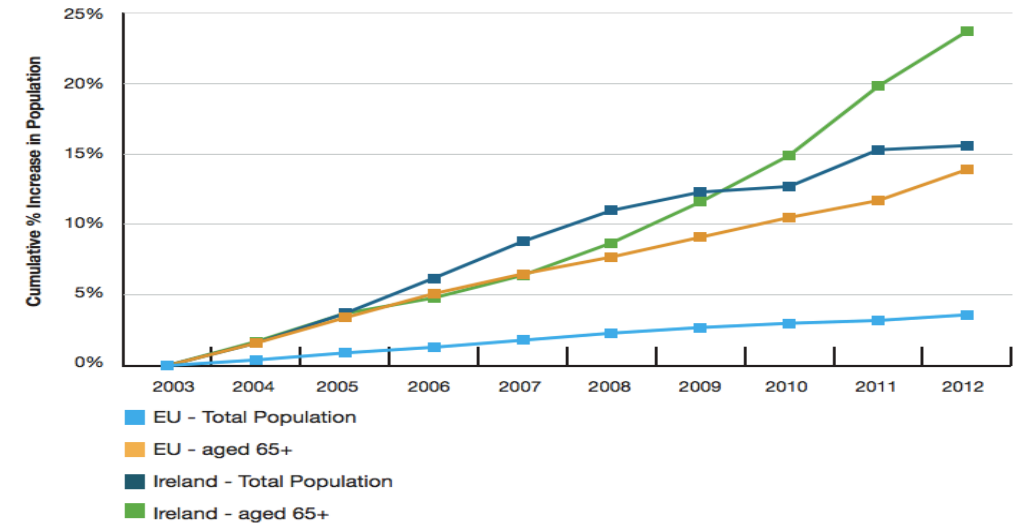
12%
2012



22%
2041



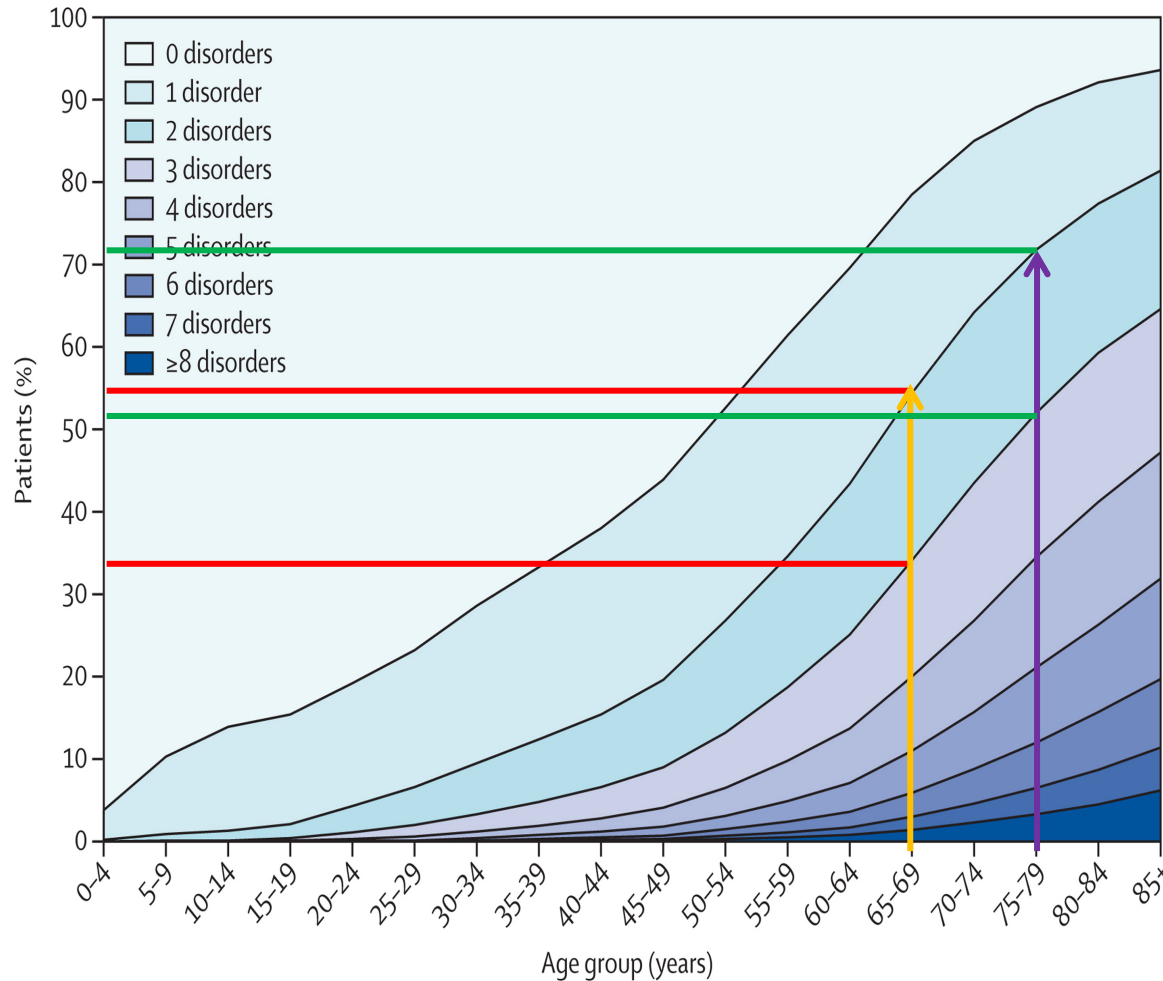
1 million people aged 75+



Cumulative percentage increase in population, all ages and aged 65+, Ireland and EU, 2003 - 2012

(Source: Eurostat)

> Age = > Risk of Multimorbidity



Barnet et al. (2012) – Lancet

- Reduce QoL + functional decline
- More likely to die prematurely and be admitted to hospital, and have longer hospital stays.
- Correlated with socioeconomic deprivation
- 50m patients in EU – €700b cost per annum
Rijken et al. (2013) - Eurohealth Incorporating Euro Observer
- US by 2030 171 million people with chronic disease – 50% with Multimorbidity. 65% of Medicare beneficiaries have multimorbidity

Wolff JL et al. (2002) - Arch Intern Med

Anderson G, Horvath J. (2004). Public Health Reports

% of patients with this condition...

...who also have this condition (% = % of all patients with the condition)



Conditions:
Diabetes,
COPD,
CHF/CHD,

Barnet et al. (2012) – Lancet

Politics: We do not deal with Multimorbidity



Empower the PwM and their care network to play an active role in managing multimorbidity

Inefficient Different clinicians, conflicting advice

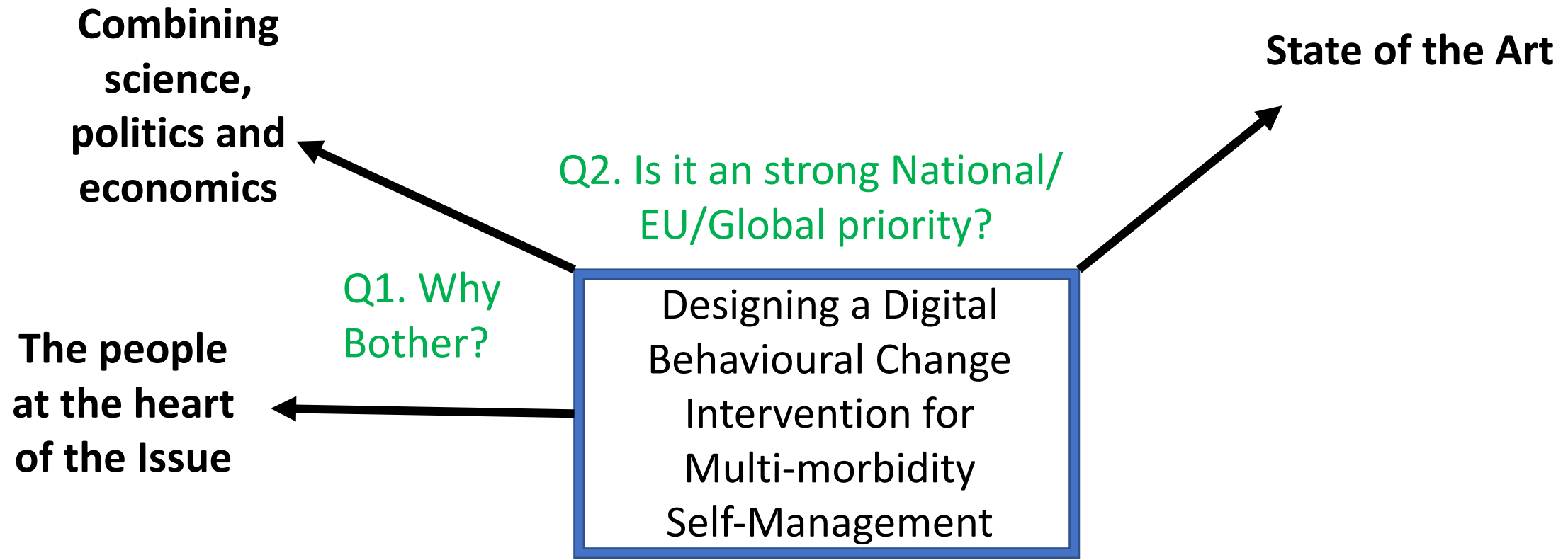
Inconvenient Hospital appointments on many different days

Repetitive Multiple appointments; Repeating medical history

Burdensome Hospital appointments on many different days

Confusing Hospital appointments on many different days

Potentially Unsafe Medication interactions and negative polypharmacy



Digital Health Research

Healthy living

Prevention

Diagnosis

Treatment

Recovery

Home care

Convergence between Professional Healthcare and Consumer markets

People wish to be engaged

Need to improve quality + cost of care

Focus on improving population health

Costs shifting to the home



Improving Patient Engagement

To adopt new lifestyle changes by using online services to empower home based care and ownership of their health.



Advancing Home-based Healthcare and use of ICT-AT

The continuum of care now incorporates telehealth, remote monitoring applications, point of care treatment, health informatics and analytics.



Improving Workflow Management

And addressing organizational change to optimize and improve the efficiency and effectiveness of services and organizations to add value to patient care and increase revenue, while minimizing problems in care delivery.



Advancing New Healthcare Models

To fit in line with flexible patient centric service models being adopted by organizations, this includes business models, affordable healthcare etc.

Digital Health Research

1. Focus on theoretical and empirical work in the areas of prevention, addiction, and adherence to medical regimens for single-disease states.
2. Lack of detail regarding solutions for individuals, health care professionals and additional support actors on how to best support the self-management efforts of those with more than 1 chronic disease

Healthy living

Convergence

People wish to

Focus on



Improving Patient Engagement

To adopt new lifestyle changes by using online services to empower home based care and ownership of their health.

telehealth, remote monitoring applications, point of care treatment, health informatics and analytics.

effectiveness of services and organizations to add value to patient care and increase revenue, while minimizing problems in care delivery.

Home care

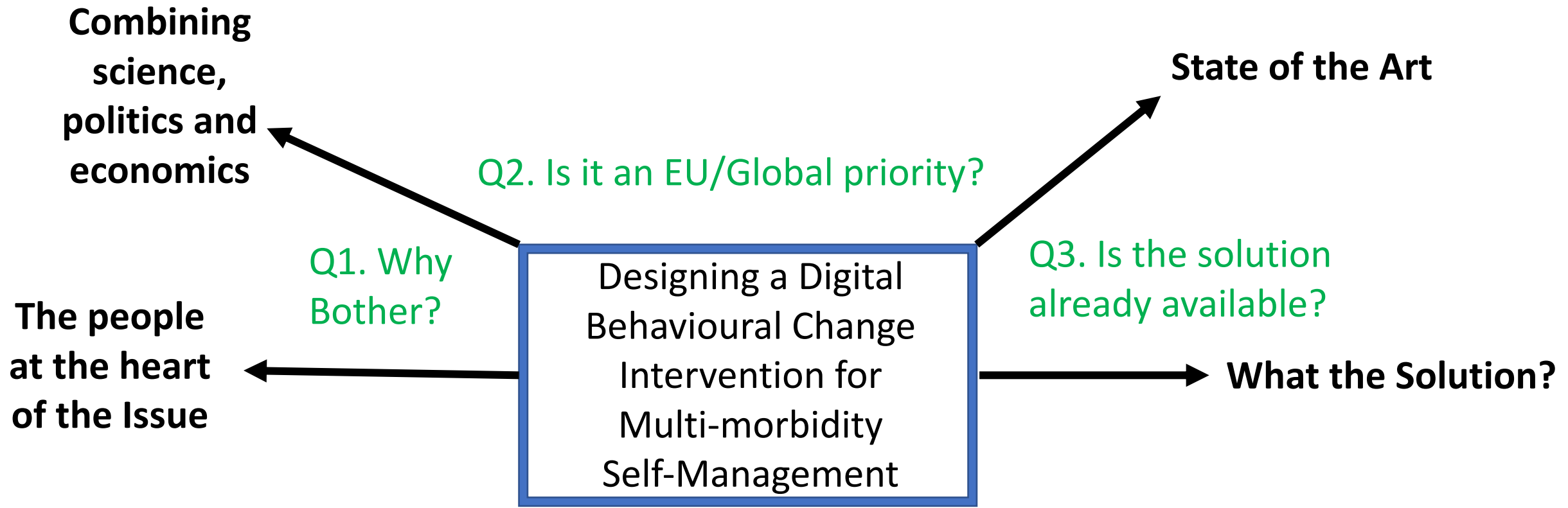
e

home



Designing New Healthcare Models

In line with flexible patient centric service models being adopted by organizations, this includes business models, affordable healthcare etc.



Focus – Self-Management

- **Self-management is a core activity**
- Self-management of multimorbidity is **challenging**, requiring engagement in **multiple tasks** such as symptom monitoring, recognition of exacerbation, medication adherence and inter-stakeholder communication.
- A **digital, integrated care approach** is a critical part of the solution.
- The main objective of our work is to design a **technology ecosystem to facilitate older adults to self-manage multimorbidity, with support from their care network.**



1. Need to better understand data between care pathways to effectively support management of single diseases
2. Develop an data aggregator to collect data new or existing technologies (**CABIE**)
3. Develop an AI (**InterACT**) to analyse data to understand overlap in disease management and direct best practices in self-management, care support and training for multimorbidity
4. Ensure the system is open: new applications can be built into it from clinical, social or community care

Meet Sarah



Sarah is 85

Conditions: Diabetes and Heart Failure

Everyday for the last 5 years she has measured her:

- Weight
- Blood Pressure
- Blood sugar

She writes readings in notebooks and brings them with her to her GP and specialist clinics that she attends for her conditions.

Sarah is finding it hard to remember when to take measurements and to write down the different readings into separate notebooks every day.

Day	Breakfast			Lunch			Dinner			Bedtime		Night
	before	insulin	after	before	insulin	after	before	insulin	after	before	insulin	
Mon 15	82	10	128	89	12	121	172	15	178	209	221	
Tue 16	92	10		160	13		170	15		206	21	
Wed 17	122	10		198	19		165	15		181	22	
Thurs 18	89	10		94	12		189	15		72	22	
Fri 19	118	11		95	12		212	16		188	22	65
Sat 20	139	16		148	13		184	15		200	22	
Sun 21	102	10		96	12		210	16		200	22	

How Can ProACT Help Sarah

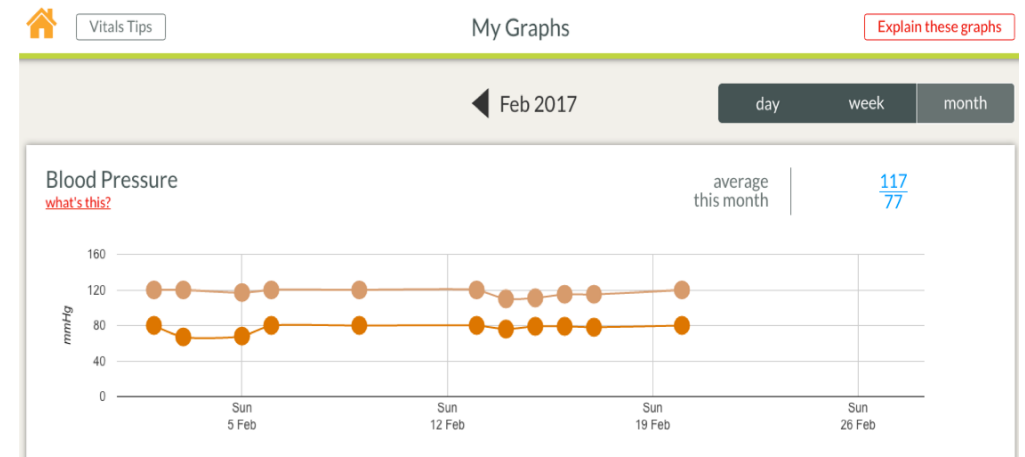
Monitoring Symptoms

- Sarah's GP recommended that she try a new technology to help her monitor her symptoms automatically
- ProACT also help Sarah to keep track of other important parameters such as sleep, activity, mood and breathlessness.



Viewing Symptoms

- Her new devices now send her readings automatically to a tablet where she can view her symptoms over the last day, week or month

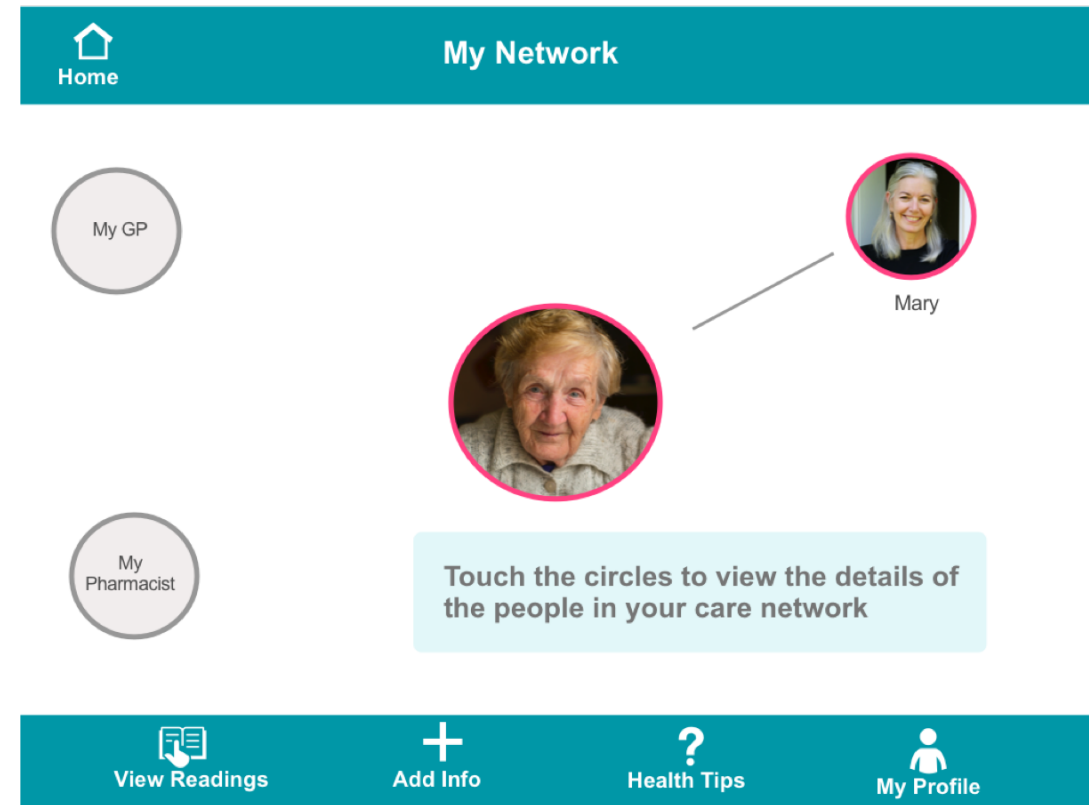


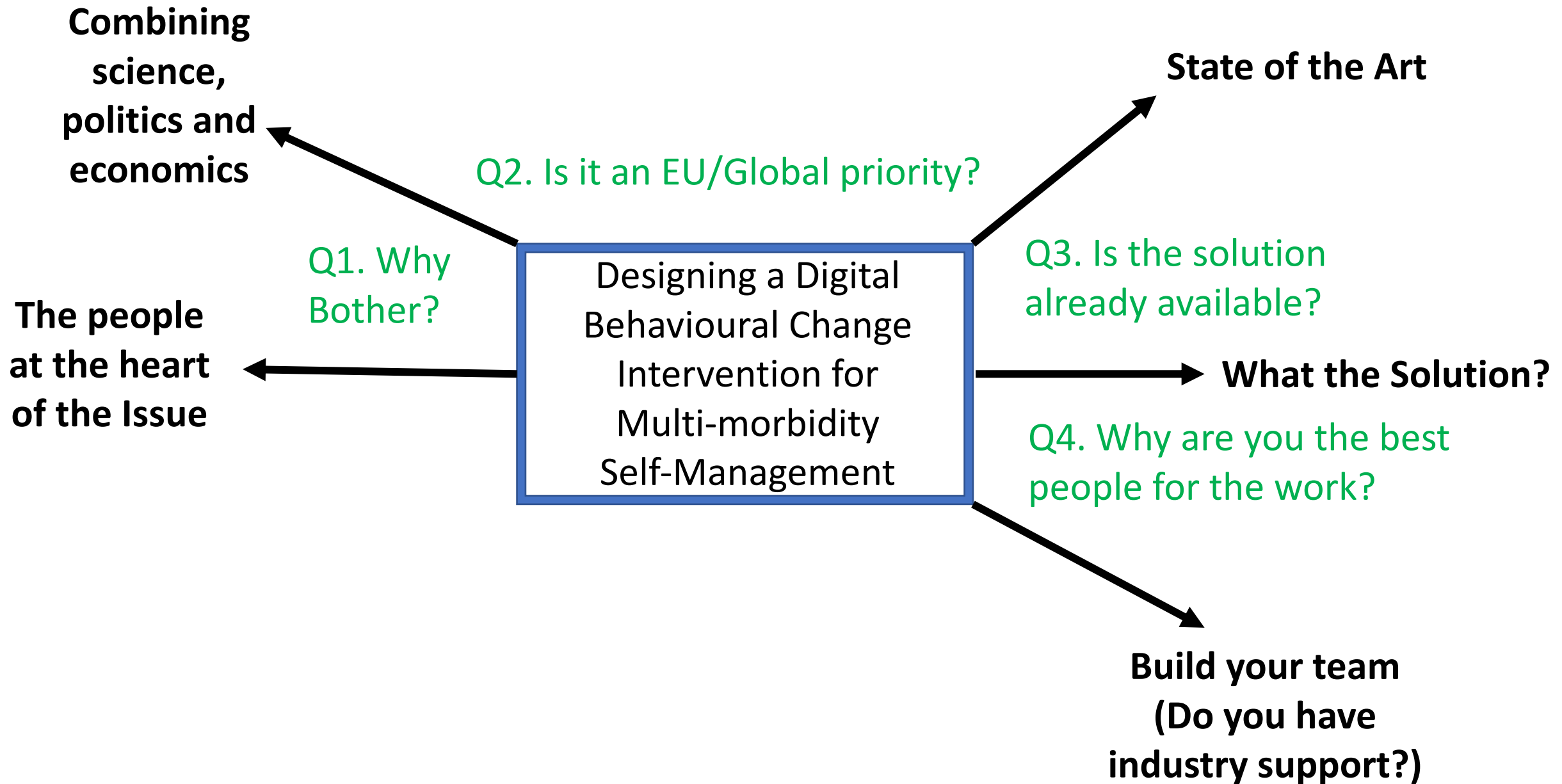
Knowledge and Education:

- The system also provides Sarah with tips that might be useful for her to manage her conditions and stay as healthy as possible.
- ProACT gives Sarah trustworthy and clear information on managing diabetes and heart failure but also on general topics such as exercise and how to get off the floor safely after a fall.

Health and Care Network:

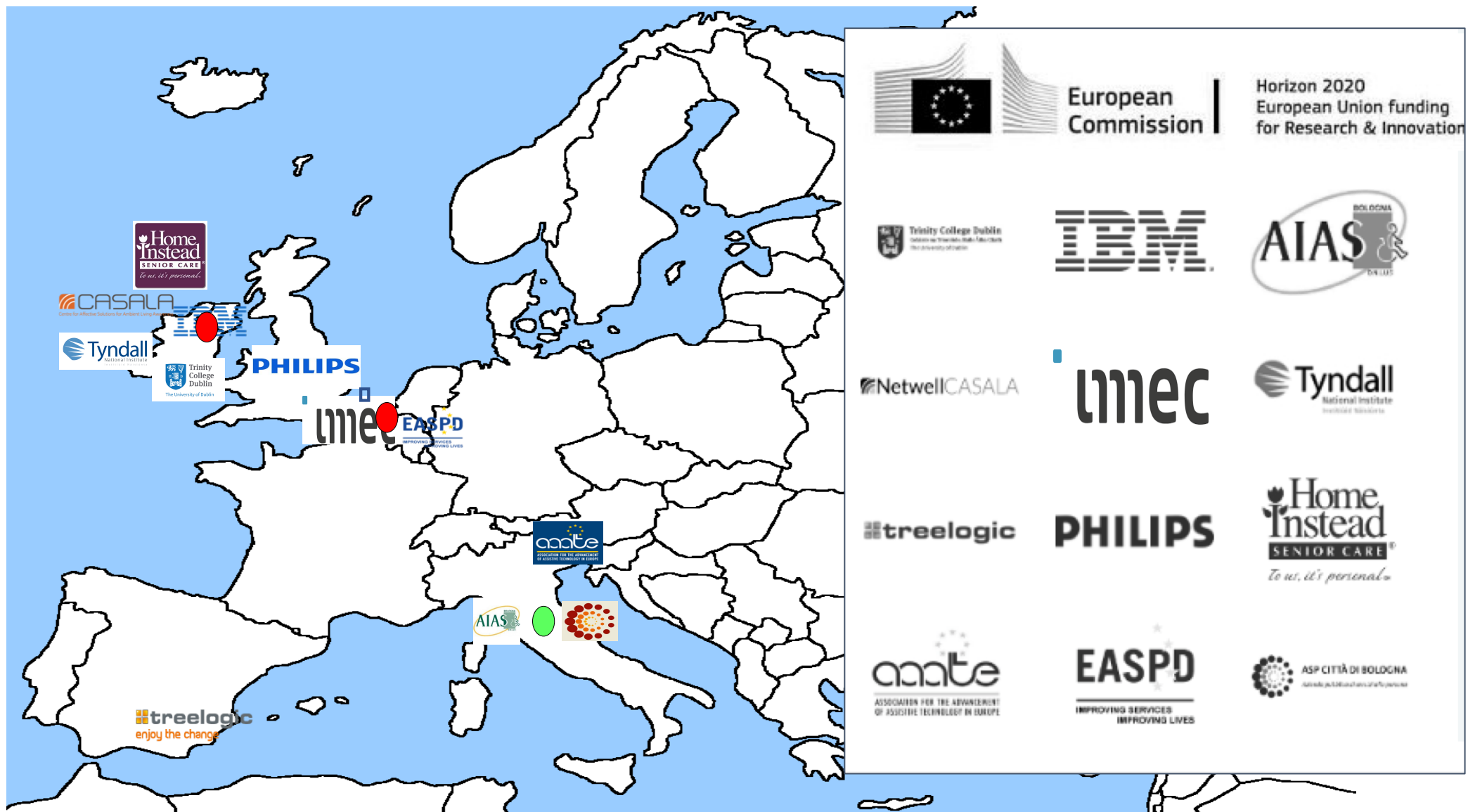
- Person driven modular ability to personalise care network
- Sarah's daughter Mary can view the health readings that she chooses to share with her from her phone.

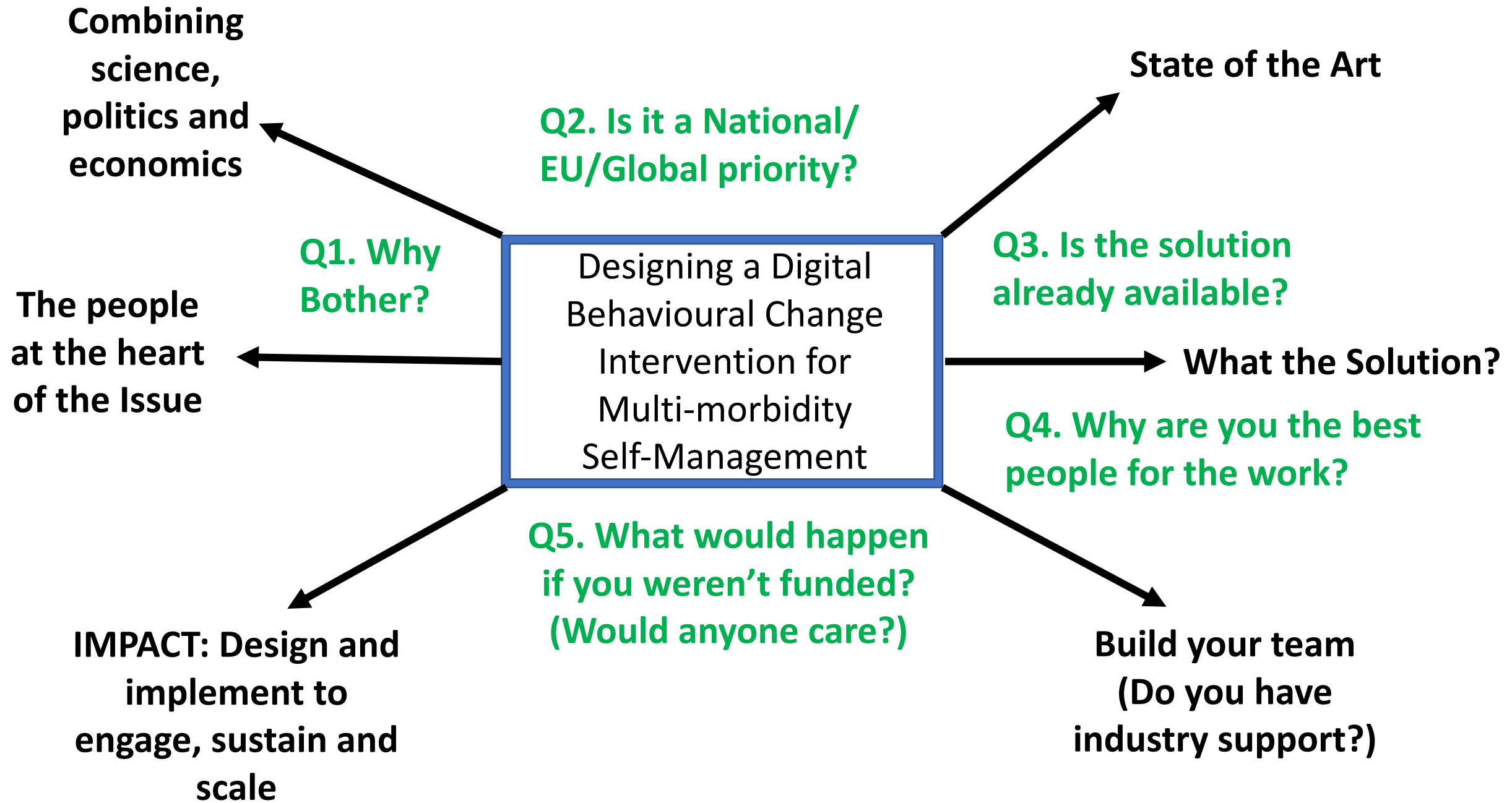




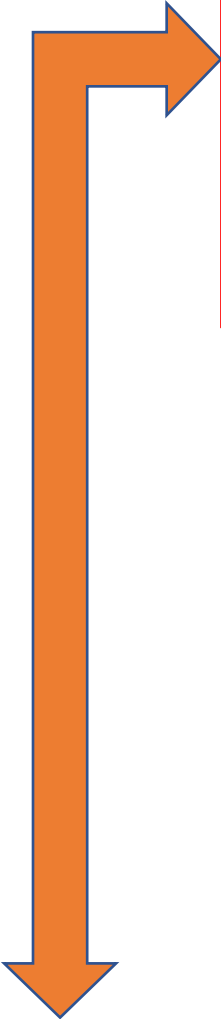


ProACT

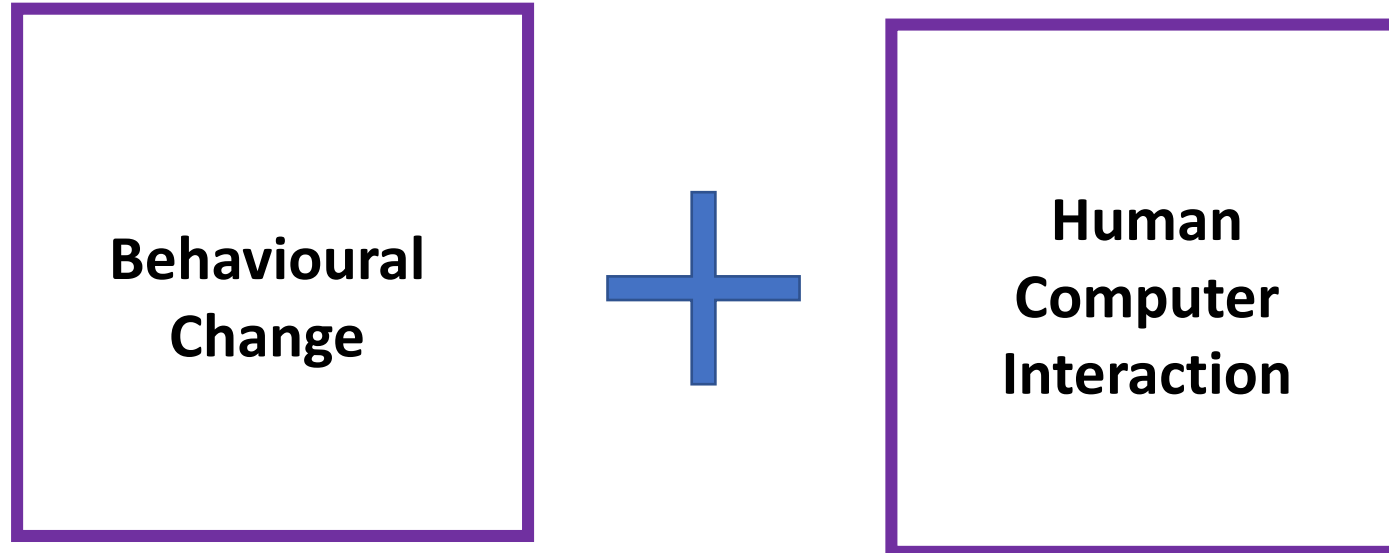




Project Outline (2016-2019)

- 
- Phase 1: User Needs Research and Scoping (**M1-9 complete**)
 - Phase 2: System Design, Development and Testing (**M9 – M40**)
 - Phase 3: Pilot Trials and further co-design and development (**M14 to M26**)
 - Phase 4: Main Proof of Concept Trial (**2018: M26/27 to M37/38**)
 - Ireland: 60 PwM and support actors
 - Belgium: 60 PwM and support actors
 - Conditions: **Diabetes, COPD, CHF/CHD**
 - **Longitudinal Action Research Design (12 months)**
 - Phase 5: Transfer Feasibility Study (**2018: M30 to M36**)
 - Italy: 15 PwM and support actors

Engage, Sustain and Scale



**User Needs
and
Requirements**

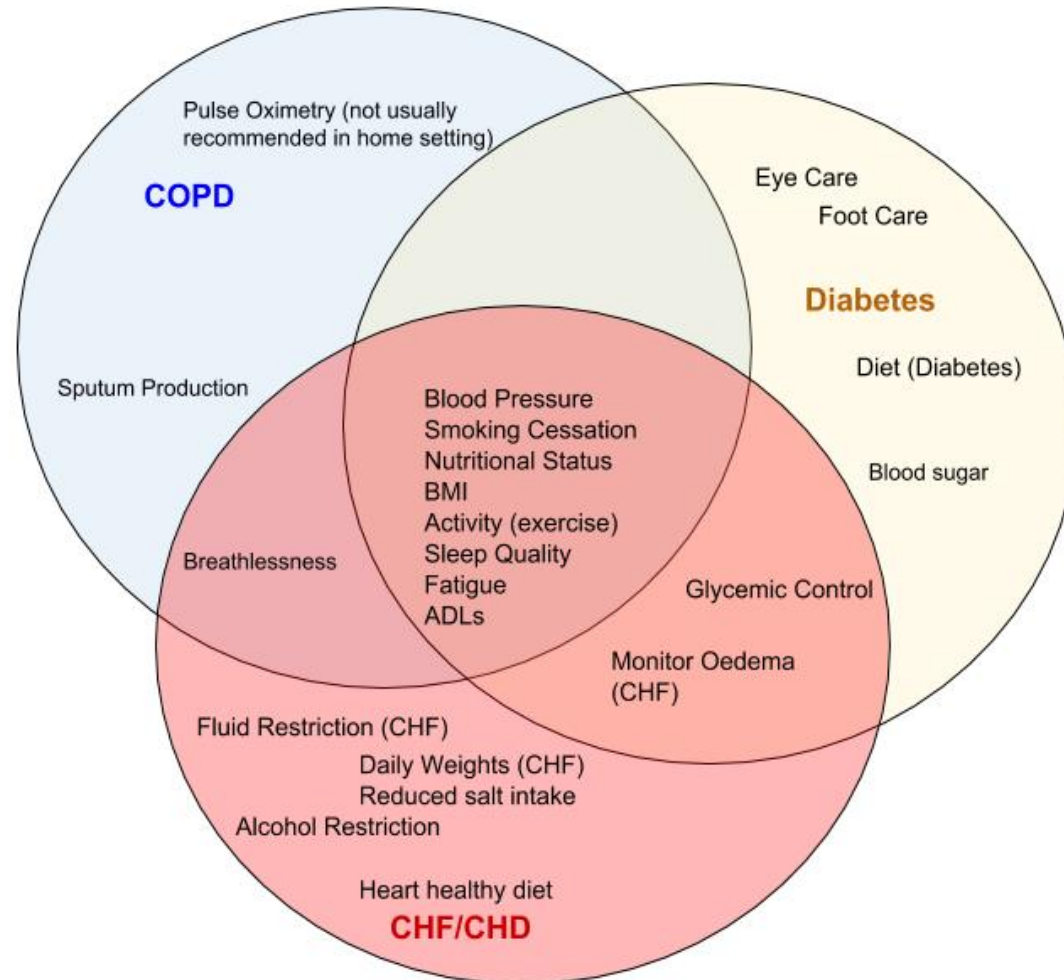
**Co-Design and
Development**

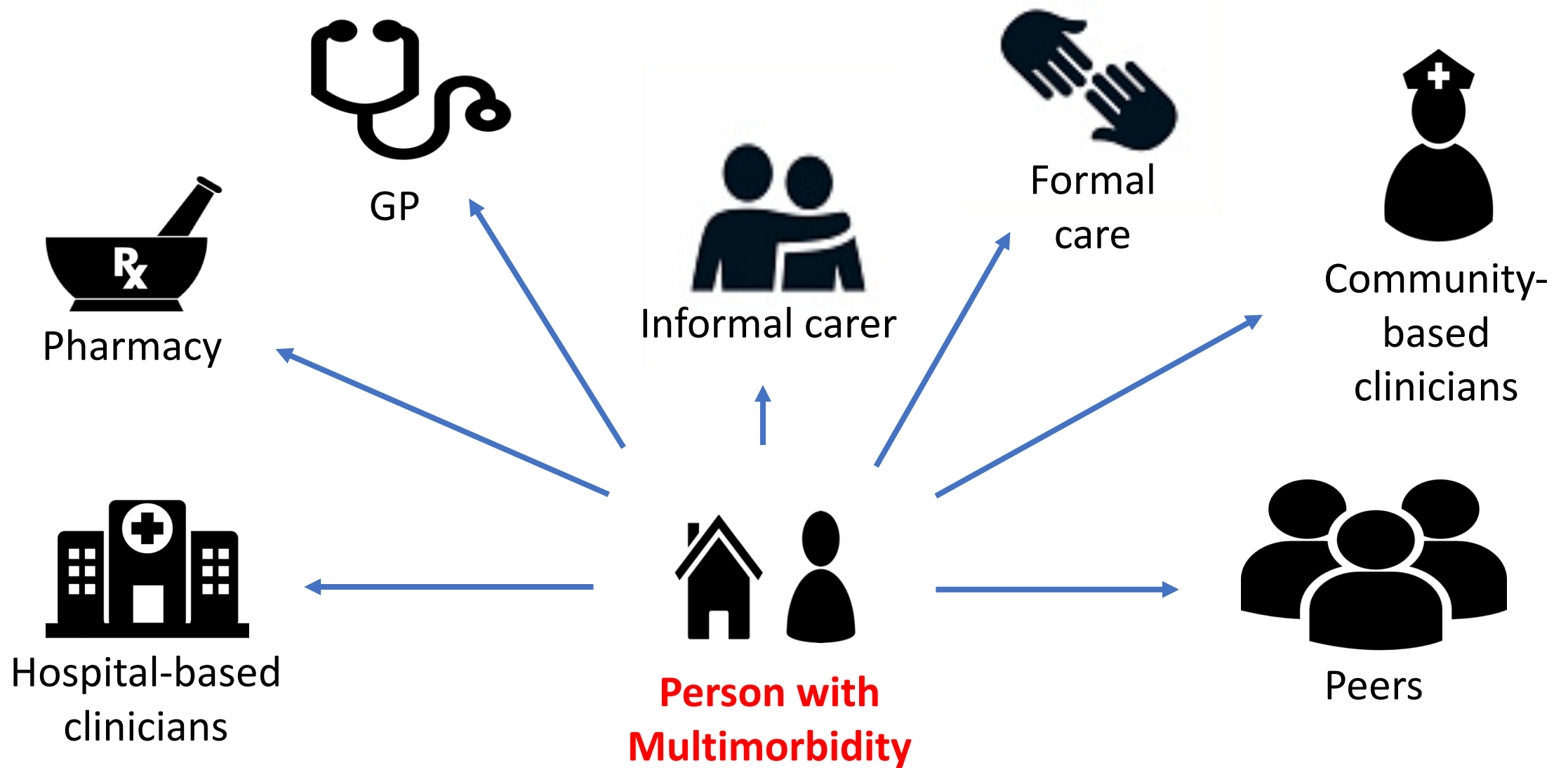
User Evaluation

1: User Requirements: Scoping

Significant desk research;
Literature and policy reviews on
disease management,
treatment and care pathways
within national contexts

ProACT Core Self Management Variables





User Requirements

- Qualitative study
- Interviews and focus groups – semi-structured; 45-120 minutes
- Demographic questionnaires (PwM and informal carer)
- 124 participants across Ireland and Belgium
- Thematic analysis
- Diabetes + CHF/CHD most prevalent
- 57% women
- 21% MCI

	Ireland	Belgium
Person with Multimorbidity	19	19
Informal carer	7	10
Formal carer	11	10
GP	6	5
Community based healthcare Public health nurse; care coordinator	3	1
Hospital based clinician Geriatrician; Clinical Nurse Specialists; Physio; Occupational Therapist; Dietician; Speech and Language Therapist; Cardiologist; Endocrinologist	12	6
Formal care provider	5	2
Pharmacist	4	4
Total	124	

Key Outcomes - PwM

- **Hugely impacts on;** Lifestyle, relationships, psychological well-being
 - **Lack of awareness of** strategies for self-management
 - **Complexities of interactions** between conditions aren't understood
 - **Maintaining independence** - remaining at home - **key motivator!**
 - **Barriers to self-management;** Lack of physical mobility; Limitations of conditions
 - **Polypharmacy:** difficult keeping track of many medications; Paper-based lists managed by PwM
- “If there was one thing I believe that would help people that end up going back into hospital, or end up being at home safer, is a much better pathway in minding their medications”**
- (Healthcare Professional interviewed in Ireland)

Key Outcomes – Support Actors

- Lack of info on **how to navigate the healthcare system** & absence of one unified care plan.
 - **Most information** received verbally/ info leaflets
 - Essential role played by **informal carers**
 - Additional training needs among **formal carers**
 - **Pharmacist** reliable/trusted source of info/support
 - **GP** – essential coordinating role
 - **Communication difficulties** between healthcare professionals
 - Currently **limited technology use** among healthcare professionals; mixed response to use; need to ensure it is accessible; benefit to collate all data in one place.
- “It’s definitely a case of detective work linking into the community, the family, and any of the MDTs that the patient is linked with. God, it’s hard.”** (Healthcare Professional interviewed in Ireland)

We employed traditional user-centred HCI techniques to help to translate this qualitative data into meaningful requirements for design:

47 key requirements across a number of categories:

1. Reducing impact of multimorbidity (3)
2. Self-management of multimorbidity (14)
3. Medication management (7)
4. Information, knowledge and education (7)
5. Sources of support (3)
6. Communication (2)
7. Technology use (11)

Whitepaper on the needs and requirements of older people with multiple chronic conditions to self-manage their health



Authors

Julie Doyle, Evert-Jan Hoogerwerf, Janneke Kuiper, Lorenzo Desideri, Valentina Fiordelmondo, Caoimhe Hannigan, An Jacobs, Lorenza Maluccelli, Emma Murphy, Suzanne Smith

Editors

Emma Murphy, Caoimhe Hannigan, John Dinsmore

Published

October 2016



2: Designing ProACT as a BC intervention

- **What is the aim of the system?**

To improve self management skills and support for PwMs using a digital rather than paper based system

- **What is the behaviour that needs to change to do this?**

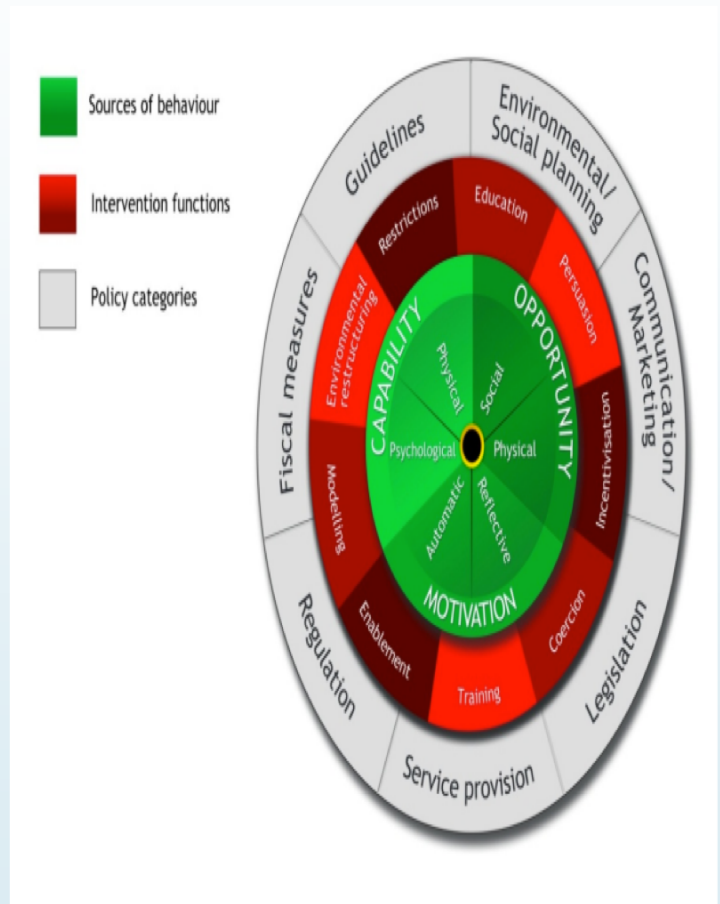
PwM - needs to change their behaviour from managing their conditions using memory and paper based strategies to a digital self management tool

- **Systematic approach to address this?**

The Behavioural Change Wheel approach involves an 8-stage process for developing behavioural change diagnoses and targeted interventional strategies.

- Synthesis of 19 frameworks to classify interventions (health, environment, culture change and social marketing)

- **Centre:** COM-B model
- **Inner ring:** Nine intervention functions (what purpose(s) the intervention serves)
- **Outer ring:** Seven policy categories

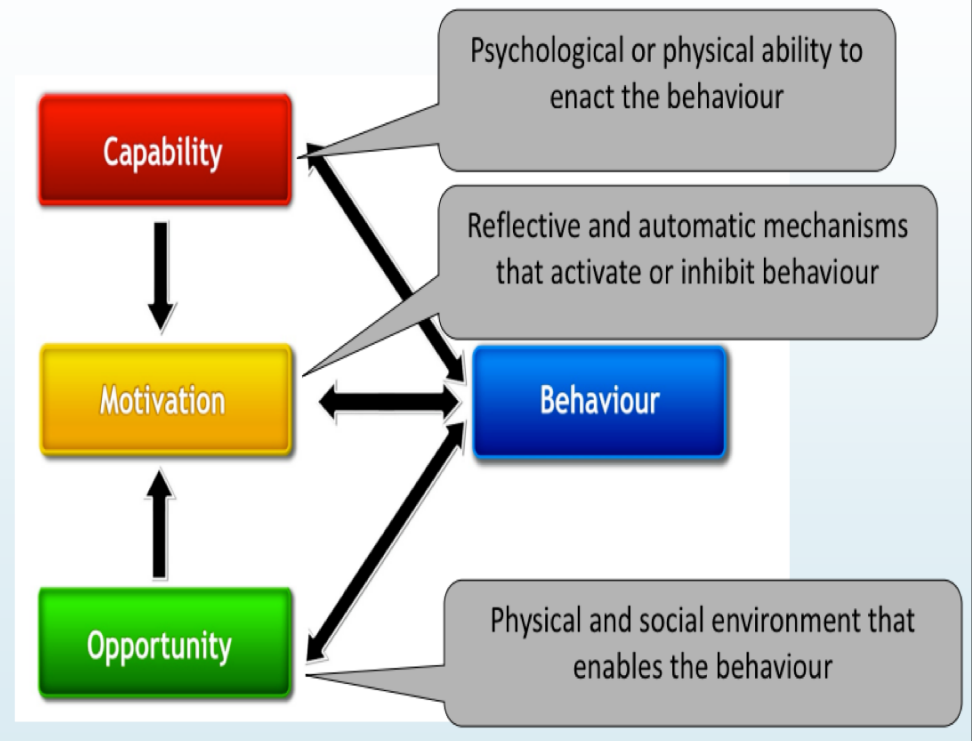


(Michie, Atkins and West, 2014)

Why apply the BCW model?

- Enabled us to design ProACT technology as a behaviour change intervention
- Understanding target behaviours within the framework of COM-B provides the first steps in **selecting appropriate intervention strategies** to bring about the desired change.
- Process allowed us to provide a framework for evaluation
- Behaviour change interventions may fail because the **wrong assumptions** have been made about what needs to change (Michie, Atkins and West, 2014).

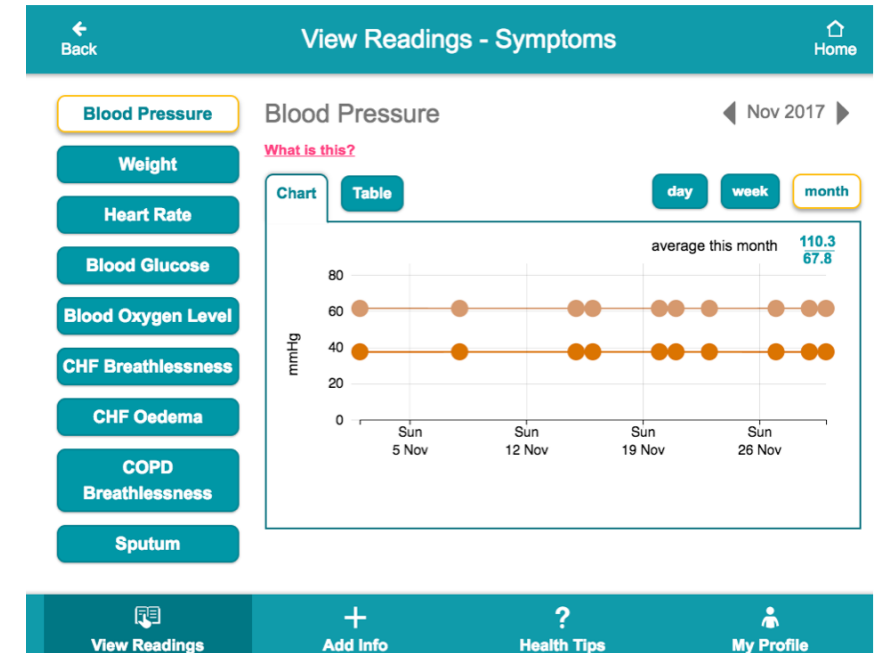
COM-B: A simple model to understand behaviour...



(Michie, Atkins and West, 2014)

BCW: Informed the UI Design

- Through the process of creating intervention strategies for each of the targets, we have translated intervention functions into additional application features.
- It has also helped us to understand the importance of features within the system that we may not have otherwise focused on (such as habit formation, social support etc.)
- Understand and pin-point BC functions and techniques in the system and helping us to define how to evaluate them and the system as a DBCI



Target 1: Measure and view key symptom readings on ProACT (Person with Multimorbidity)

Intervention functions	COM-B components served by intervention functions	BCTs to deliver intervention functions
Education	Psychological capability Reflective motivation	5.1 Information about health consequences 1.2 Feedback on behaviour 2.7 Feedback on outcome(s) of the behaviour 7.1 Prompts/cues
Training	Psychological capability Automatic Motivation	4.1 Instruction on how to perform a behaviour. 6.1 Demonstration of the behaviour 8.3 Habit Formation.
Environmental Restructuring	Physical opportunity	12.5 Adding objects to the environment 12.1 Restructuring the physical environment.
Persuasion	Reflective motivation	9.1 Credible source
Enablement	Social opportunity	3.1 Social support
Incentivisation	Reflective motivation	10.4 Social reward

BCW: Implications for Analytics

- BCW has highlighted the importance of *User Engagement metrics and analytics* to help us to evaluate ProACT as a BC intervention
- The BCW has highlighted the need for the *personalisation* of behaviour change techniques and interventions which we have considered in the design of our CareAnalytics (PROACT Artificial Intelligence - IBM)

1. Data cleaner
2. Probabilistic Health and Wellness Profile Builder
3. Goal Recommender
4. Education Recommender
5. User Engagement Analyser



GOAL SETTING

- **Presents particular challenges and complexities** for multimorbidity. Due to link with age additional conditions impact on ability to achieve goals.
- **S.M.A.R.T goals (Doran, 1981) were not common practice** for PwM or care network. Goals were general and not measureable.
- **Issue:** Lack of awareness around types of realistic goals to set, lack of support from care network (time, not wanting to overload PwM, sense PwM should self direct, care network insufficient data to inform goals). Peer rather than clinical support a key motivator.



Evaluating ProACT as a BC Intervention

Each of the BC targets will be evaluated by:

- **Analysing system usage statistics** – how participants engage with specific features of the system i.e. measuring symptoms, recognising change, view education content
- **Quantitative trial assessment data (assessment measures)**
- **Qualitative interview data** – Thematic Analysis - Understand experiences

23 key metrics including: Session length, dashboard time, reflection screen time, view readings time, view reading screen responses health tips time, my info time, button presses on each screen, daily app opens etc.

19 Assessments including: Usability (T2;T3;T4), Burden (T2;T3;T4), technology proficiency (T1;T4), social connectedness (T1, T4), QoL (T1-T4), self efficacy (T1-T4, illness perceptions (T1-4), self-management (T1-T4), Demo (T1), med lists (T1;T4)

Interview schedules, reflect key assessment areas above.

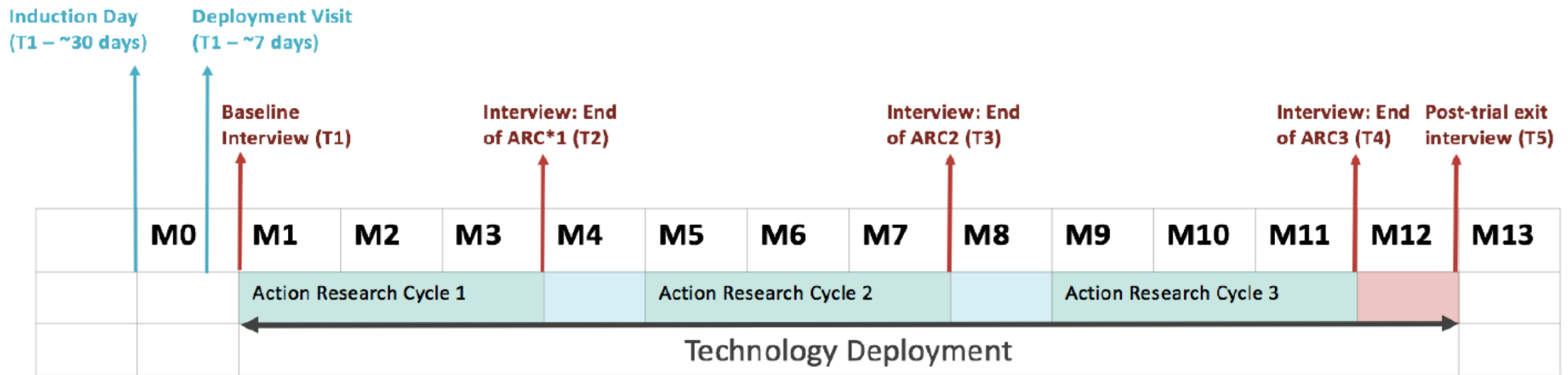
3: Co-design Process

- A subset of participants were invited to take part in co-design activities
- **Goal:** ensure user involvement at all stages
- Validate findings from phase 1; further explore some areas; support design of ProACT ecosystem and CareApps;
- **Sessions used to:**
 - Inform the main features and concepts
 - Inform the interface design
 - Med Application and feedback on initial designs



Review, Confirm, Refine (Redesign)

Study Timeline: PwM Participants



*ARC = Action Research Cycle

Technology Deployment Colour Codes

	Action Research Cycle
	Re-design/ Re-development
	Phased technology withdrawal

Proof of Concept Study: Learn and confirm how it works

Conclusions

- Digital health **holds promise** but designing and delivering DBCI's is **challenging**
- Key to our success is to design interventions based on a **strong theoretical foundation – strong PoC**
- **Technology advances rapidly** - Agile, iterative methodologies are needed to develop strong PoC's before larger studies
- **Funding for larger studies** is required
- **Multimorbidity/Comorbidity – May unlock** how we can manage diseases on a single platform
- **AND FINALLY....**

How can eHealth improve care for people with multimorbidity in Europe?



Council of the
European Union

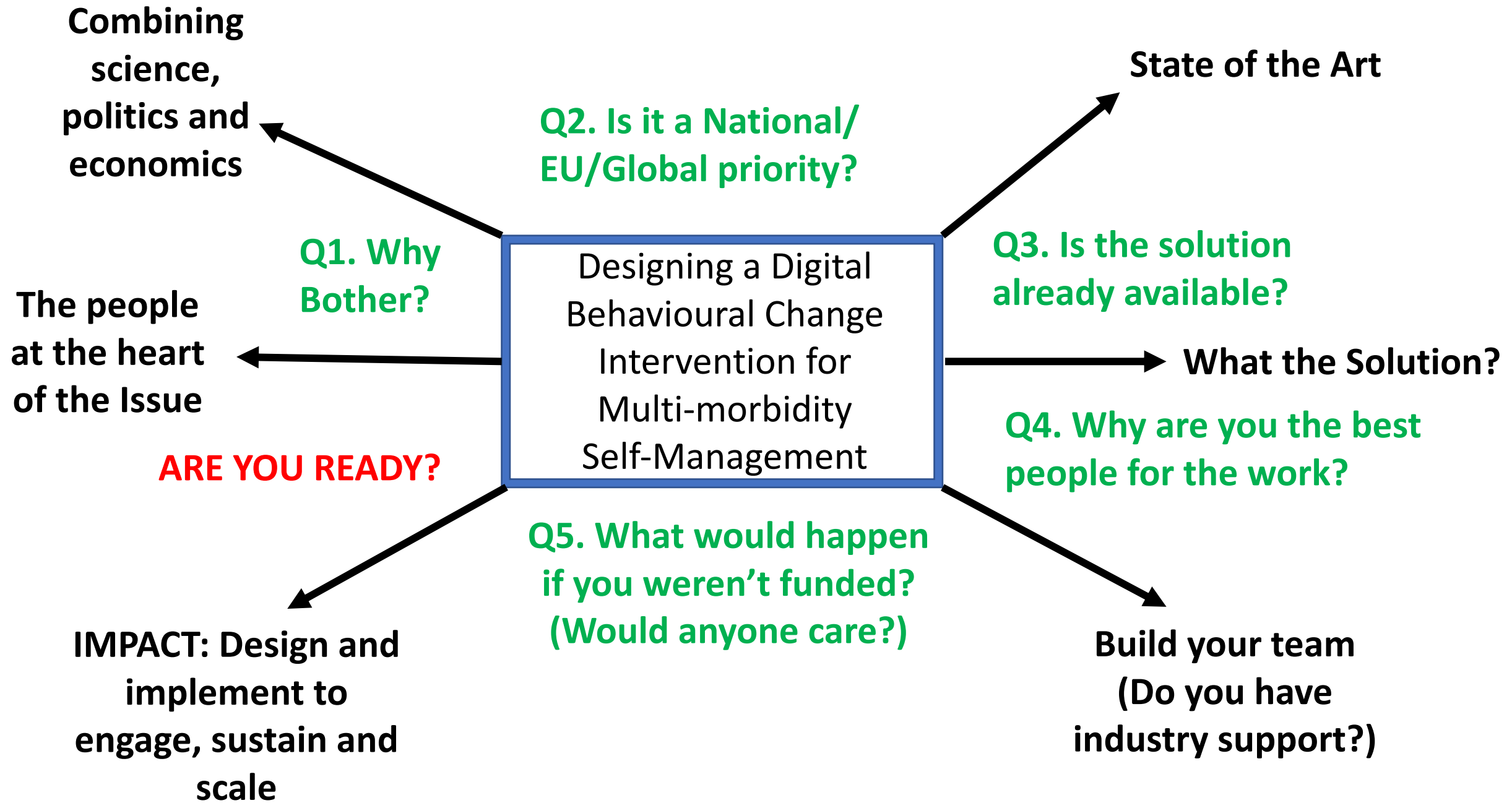
Brussels, 28 November 2017
(OR. en)

14078/17

SAN 399
TELECOM 272
DATAPROTECT 177

NOTE

From:	General Secretariat of the Council
To:	Council
No. prev. doc.:	14076/17 SAN 398 TELECOM 271 DATAPROTECT 176
Subject:	Employment, Social Policy, Health and Consumer Affairs Council meeting on 8 December 2017 Draft Council conclusions on Health in the Digital Society - making progress in data-driven innovation in the field of health – Adoption



ProACT

Thank You!

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