Source: *Digital Health Age,* **Credit**: *Google images*

Engaging patients and the public in eHealth

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Background

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Societal Changes

Health Challenges

Potential Solutions

eHealth Research

Clinical Research
- Lots of pilot studies & clinical trials (RCTs)
- Focus is on **one** technology with **one** patient group

Implementation Research
- eHealth implementation is **complex** in the **real-world**[1]
- **Generic** factors affect technology regardless of clinical condition
- Implementation research focuses on usability/adoption
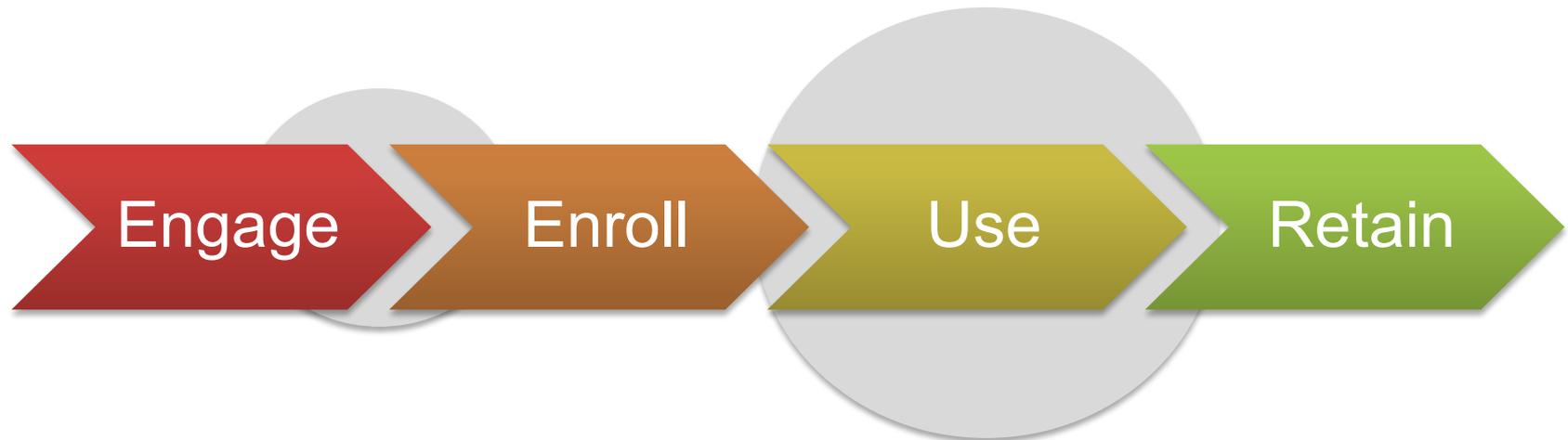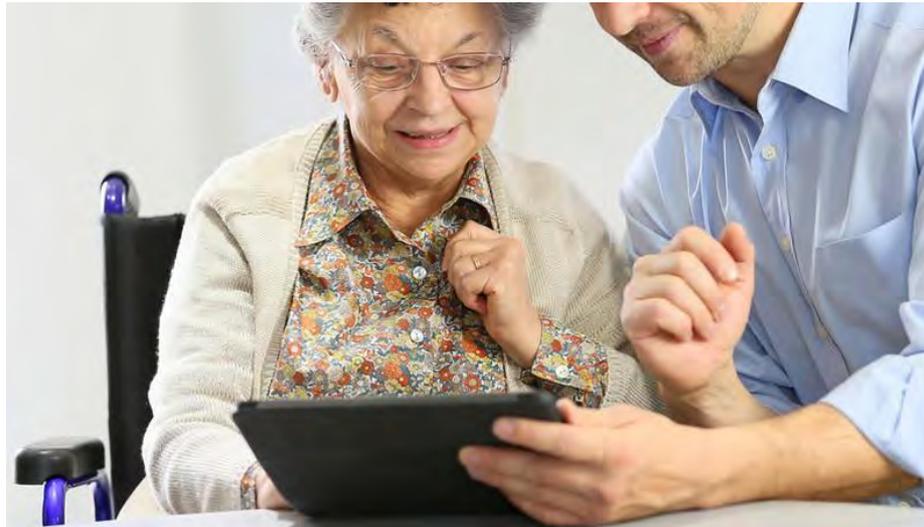- Little known about engagement or enrolment

Engage → Enroll → Use → Retain

Figure 1: *Implementation Process*

Aims

1. What **factors (barriers and facilitators)** do patients and the public experience during engagement and enrolment to eHealth?

2. What strategies are used to engage and enroll **patients and the public** in eHealth?

Methodology

Systematic review of the qualitative literature[2]

6 databases searched using MeSH and free text terms

19 studies included

Thematic analysis using framework approach
Underpinned by Normalization Process Theory (NPT)

Four themes affecting engagement and enrolment[3]

| 1,423 records identified through database searching (duplicates removed) | 15 additional records identified through reference, footnote and citation tracking |

| 1,448 titles screened | 451 excluded |

| 997 titles and abstracts screened | 707 excluded |

| 290 full papers screened | 271 full text articles excluded due to: non English language, review paper, not having a person-centred digital health intervention, not occurring during the engagement or recruitment phase, no qualitative methods used or being a conference proceeding |

| 19 studies included in the qualitative systematic review | |

York Health Economics Consortium

Exploratory Case Study

Delivering Assisted Living Lifestyles at Scale (dallas) programme[4,5]

Secondary data analysis of interviews (n=47)
Health Professionals, Health Service Managers, Voluntary Sector, Technology Industry, Government Agencies
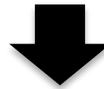
Primary data collection of interviews (n=14) & focus groups (n=5)
Patients, Carers, Public, Health Professionals

## Inductive thematic analysis using framework approach

Deductive analysis using Normalization Process Theory (NPT)

Q2 Results – Strategies Used

ENGAGEMENT	ENROLMENT
Advertising (Indirect) - Electronic media e.g. television screens, digital notice boards, radio - Online media e.g. email, social media, websites, Internet communities/forums - Print media e.g. newspaper ads, personal letters, posters, flyers	**Automatic** - Consent is assumed and a digital profile or account created
	Electronic - Register online via a website
	Paper based - Complete a paper registration form
Personal Contact (Direct) - During consultation with a health professional or employer - Research or management staff within a healthcare facility - Family, friends or peers - Co-design activities	**Personal Assistance** - Healthcare professional helps to create a digital profile or account
	Telephone/Mobile - Telephone registration line - Send a SMS text message

Q1 Results – Barriers/Facilitators

Five themes affect patient/public engagement & enrolment in eHealth
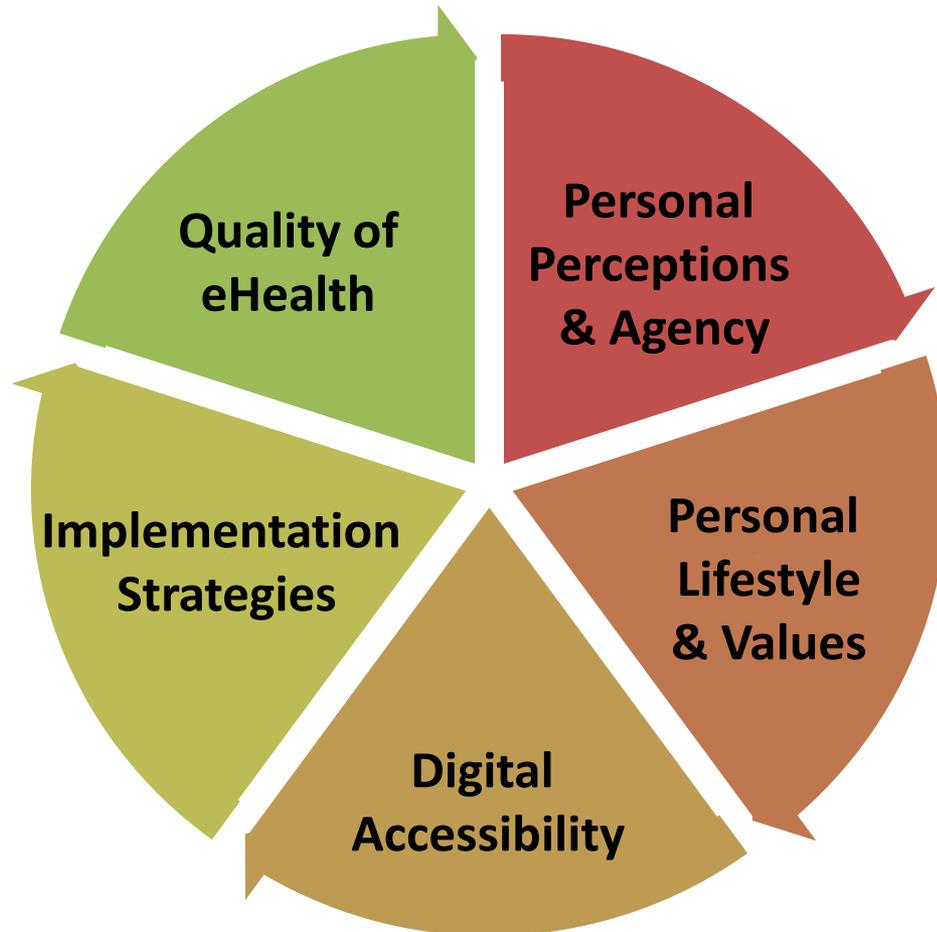
1. Personal Perceptions & Agency

Barrier/Facilitator

- Motivation to understand & improve health
- Awareness or understanding of eHealth
- Choose time & location of interaction with eHealth
- Control health data

"if you are in a lunch break and you're sat at your desk just on the Internet and you're not moving and you're eating something that's not good and then you get a reminder and it's just: 'have a walk!', or something. Straight away there is a trigger in your mind and you think: 'yeah, that's right, I can do that!"
– Systematic Review, Facilitator, Employee, email & SMS physical activity promotion

"The availability, the cost, the lack of profile at the moment is just maybe hindering it, so you say telecare, telehealth to 99.9% of the population and they'll go what?"
– Dallas Midpoint Interview, Barrier, Voluntary Sector, Participant 30, Dec 2013

Source: *Sitekit*
Credit: *Google images*

2. Personal Lifestyle & Values

Barrier/Facilitator
- Personal lifestyle
- Trust in the privacy and security of electronic health information
- Language

*Source: Toddleabout, **Credit**: Google images*

"people don't necessarily care about their own health, you know they've got more important matters like kids, trying to pay the mortgage or the rent, a whole range of issues that you know can cause a great deal of stress and things so health isn't necessarily their top priority"
- **Dallas Endpoint Interview, Barrier, Voluntary Sector, Participant 50, June 2015**

"I'm very wary of the internet, we leave digital footprints wherever we go and you never know what's going to come back and haunt you and I think the more that you are in a professional working environment the more you need to be careful about what you put online"
– **Systematic Review, Barrier, Patient, Online CBT**

3. Digital Accessibility

Barrier/Facilitator

- Access to technology e.g. Internet
- Cost of eHealth
- Digital literacy skills

Source: https://www.livingitup.scot/ , *Credit*: *Google images*

"I don't even have 3G, I have no signal on my phone where we are, it's terrible"
- **Dallas Focus Group, Barrier, Health Service User, Participant 87, April 2015**

"you know, a lot of people, we imagine that lots of people out there with iPhones but, you know, some of the population can't afford them and don't dare to have them because they get nicked all the time" – **Dallas Baseline Interview, Barrier, Health Service Manager, Participant 7, Nov 2012**

"But you've still got generations of people who that is not suitable for, because that's not how they've been brought up. So at the moment we're in that transition of having people that actually don't have the skills and don't have the mindset of the way things work, and people who socially don't have that option at the moment"
– **Dallas Focus Group, Barrier, Health Professional, Participant 93, April 2015**

4. Implementation Strategies

Barrier/Facilitator
- Branding and advertising
- Personal contacts & recommendations
- Tailored support e.g. health professional
- Clinical accreditation and endorsement

Source: Chron, Credit: Google images

"the best part of it for me was my son is very techy and he loved it and really got into it and he can show me round it and then my husband has got into the techy stuff as well now"
- Dallas Focus Group, Facilitator, Patient, Participant 107, March 2015

"I would probably if I knew that the physician would access that prior to an appointment. If the physician didn't read it, if it was more of a personal thing [just for me to do], I don't know if I would kind of follow through with that."
– Systematic Review, Barrier, Patient, online EHR (patient portal)

5. Quality of Technology

Barrier/Facilitator

- Usability when registering
- Integration of eHealth
- Trust in digital information or interaction
- Quality of digital information or interaction

Source: 123rf, Credit: Google images

"I And we, sort of, went through some of the teething problems initially of trying to work out what mums need…the input just put on each screen in order to log on and set up the accounts and those things. And realising how long it took sometimes just to register in the first place"
**– Dallas Focus Group, Barrier, Health Professional, Participant 81, April 2015**

"there is a resistance to change, which is led by the idea, well, you know, if you put a box in my house, does that mean I'm not going to see the doctor as often?"
- Baseline Interview, Barrier, Industry Sector, Participant 5, Oct 2012

"I don't think you would get the same feeling as if you were one-to-one in a room. You get more, you get to know the other person, so in a way you would. To me it would be like talking to a machine." **– Systematic Review, Barrier, Patient, Online CBT service**

Digital Health Engagement Model (DIEGO)
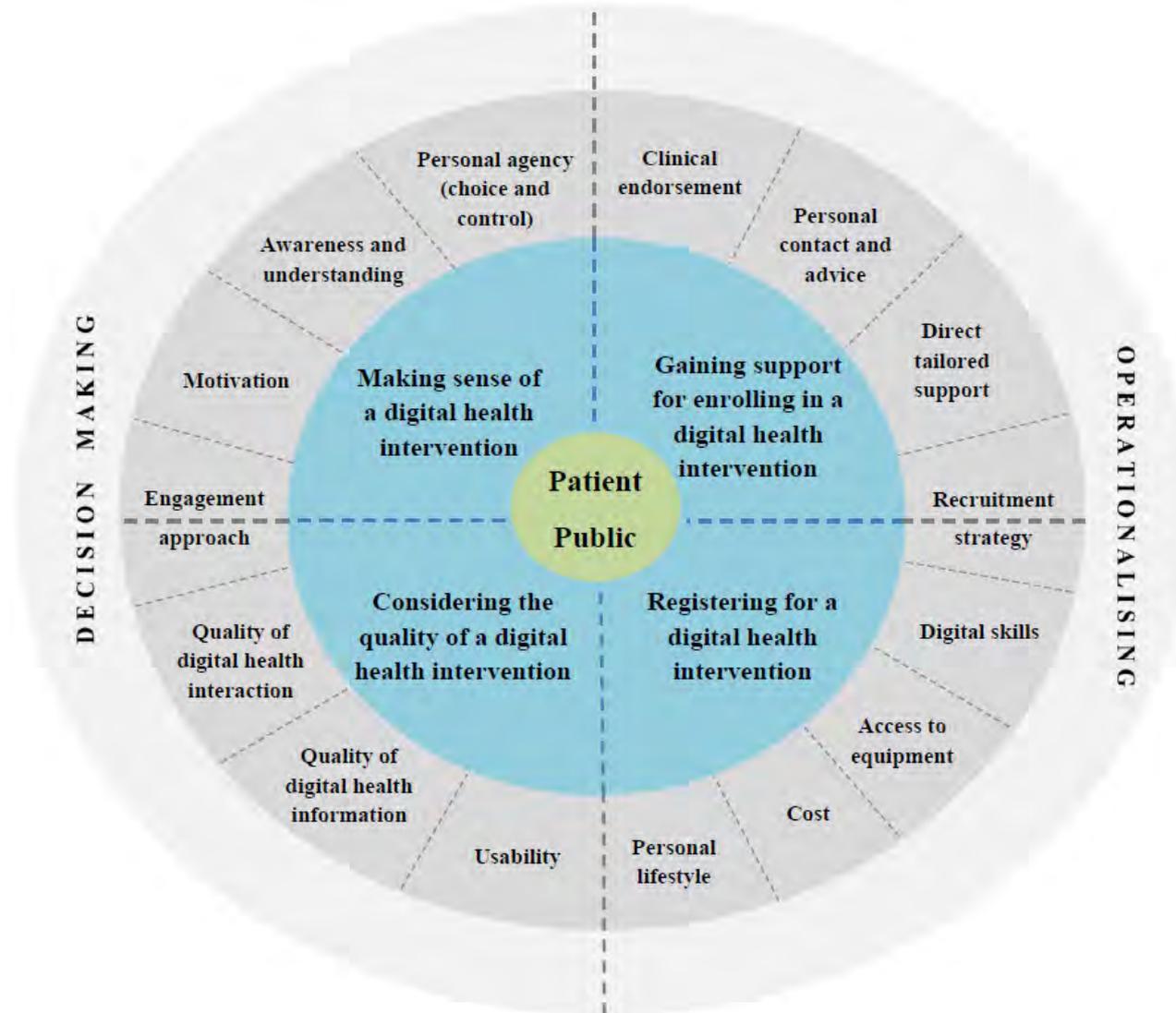
Recommendations

1. **Raise profile** of digital health products and services among patients/public to increase awareness and understanding of benefits/risks

2. Technology should enhance **communication, social interaction** and relationships with formal and informal care providers and peers

3. **Clinical accreditation** and endorsement will be necessary to promote some DHIs and encourage patients/public to sign up to them

4. **Promotional activities** should target patients and their formal and informal care networks to improve uptake of digital health

5. Engagement and recruitment strategies along with the products and services should be **better designed and tailored** where possible

6. Investment is needed in **digital up-skilling** and **technical infrastructure** if digital health uptake is to be enhanced

7. **Better funding models** need to be put in place to help ensure equity of access to digital health products and services

8. Public should be made more aware of the **potential security risks and regulations** in place to protect them

Conclusion

Source: ghcmychart.com, **Credit**: Google images

Outcome

• Useful recommendations that could improve uptake of eHealth

Study Limitations

• Secondary analysis

• Difficulty recruiting "consumers"

Future Research

• Scoping review

• Test the DIEGO model

• Develop eHealth readiness toolkit

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Thank You. Any Questions?

Source: paindoctor.com, **Credit**: Google images

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Siobhán O'Connor is a Lecturer in Nursing at the School of Health and Social Care, Edinburgh Napier University, United Kingdom. She has a multidisciplinary background with honours B.Sc. Nursing and B.Sc. Business Information Systems. She teaches nursing and informatics at undergraduate and postgraduate level and is a Fellow of the Higher Education Academy. Siobhán is currently completing her doctorate at the University of Glasgow, exploring patient and public engagement and enrolment in digital health. She is a member of the Royal College of Nurses (RCN) eHealth Forum, the British Computer Society, the American Nursing Informatics Association (ANIA) and the RSE Young Academy of Scotland.

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