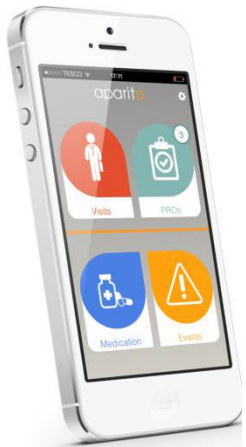# Patients and the Digital Revolution

se studies of remote patient monitoring: use of wearables

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The Digital Patient

The digital patient is here – but is healthcare ready?

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What is Patient Generated Data?

Patient-generated data (PGD) are health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) [3]

They include, but are not limited to:

- health related events / symptoms
- medication adherence
- biometric data (wearable devices)
- ePatient Reported Outcomes (PROs)

Patient-generated data (PGD) are distinct from data generated in clinical settings and through encounters with health care providers in two important ways:

- Patients, not providers, are responsible for capturing or recording these data.
- Patients decide what data to share, and with which health care providers / researcher to do so.

Examples include physical activity using wearable devices, and medication adherence and ePRO using a mobile app.

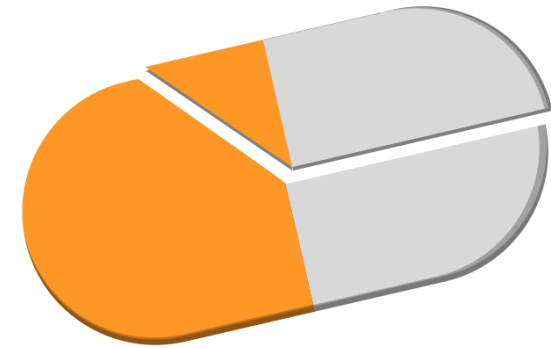PGD most easily captured digitally in today's world.
Digital Biomarker to become an important concept.

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Why do we need PGD?

The Problem

Capturing clinically meaningful patient-data is challenging.

Clinical decisions difficult to make

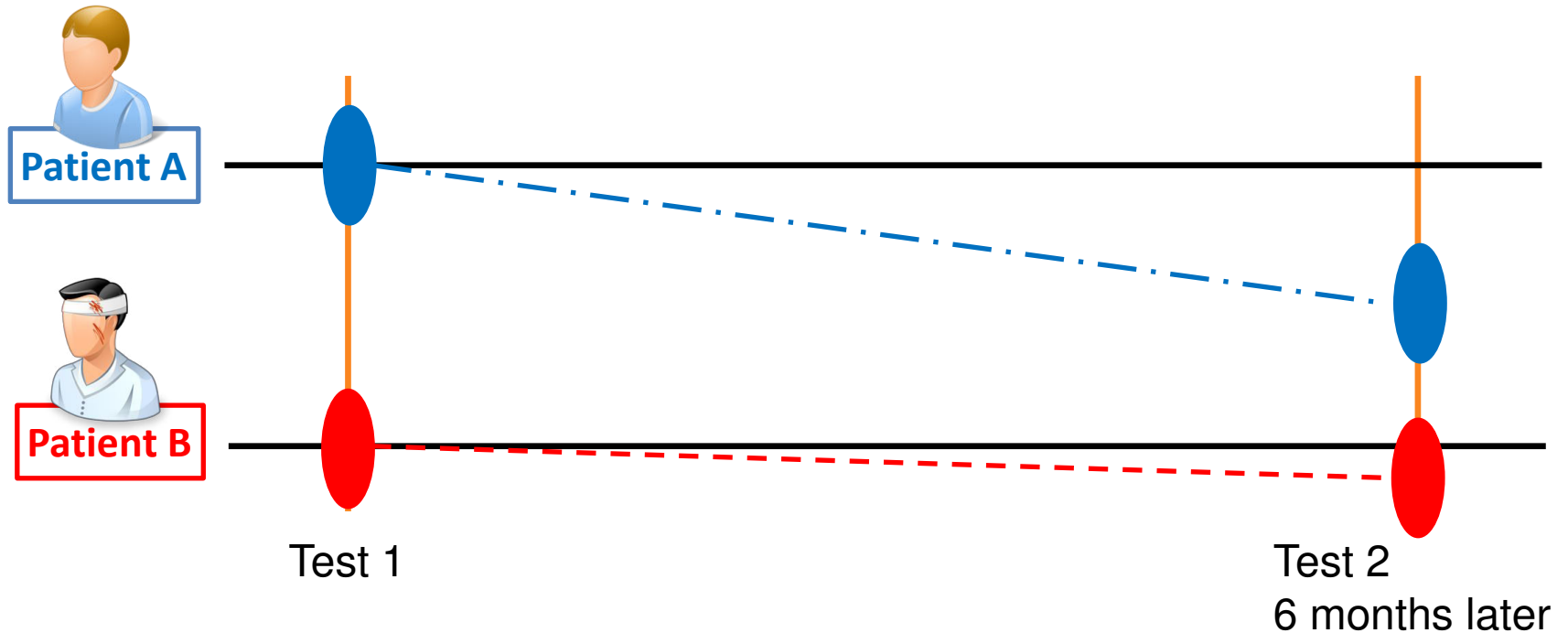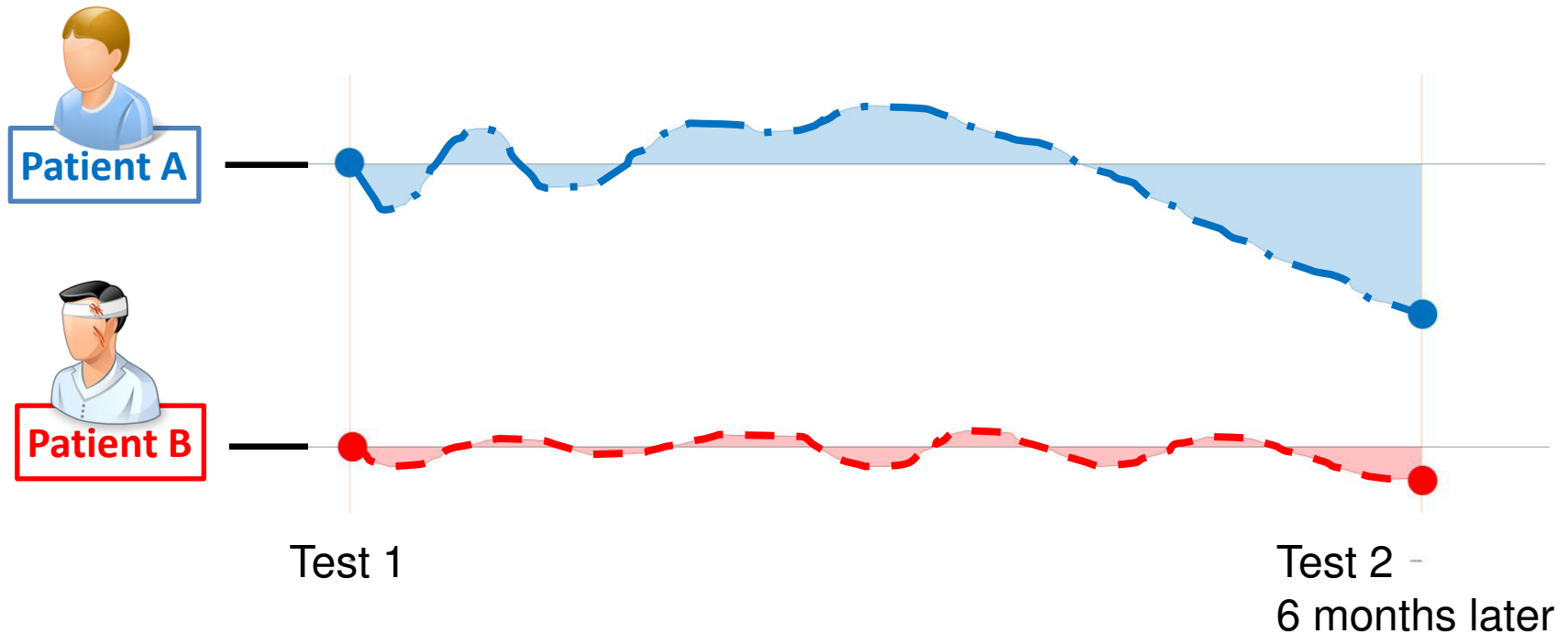Clinical trials fail

Reimbursement applications fail

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What the Doctor **sees**…

Patient A

Patient B

Test 1

Test 2
6 months later

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What the Patient **experiences**…

Patient A

Patient B

Test 1

Test 2
6 months later

"99 percent of patient activity happens outside of the hospital or clinic,
beyond the scope of the [electronic health record] EHR"

Why do we need this technology?
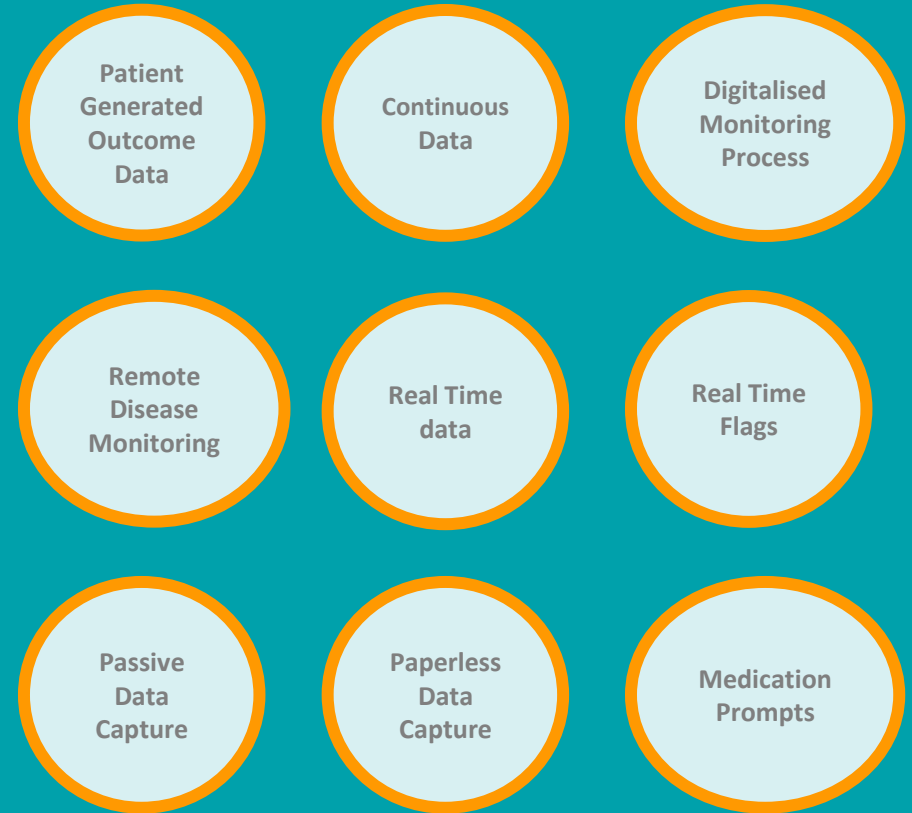
Increasing the probability of success and lowering costs

✓ Improve remote patient monitoring, and natural history understanding

✓ Drive value from Patient Generated Data – demonstrate what's important to patients

✓ Reduce the amount of monitoring intervention that contributes to a lower quality of data captured.

✓ Conduct studies anywhere in the world where there's an Internet or 3G connection.

✓ Conduct studies in geographies without having to be too concerned about the costs or practicalities of that locations infrastructure.

✓ For selected studies / diseases / drug type – reduce the number of patient visits and reduce the overall cost of running a study.

✓ Bring objective, outcome based data to Drug Application and increase the

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Ambition for Patient Generated Data

Design to overcome clinical and regulatory roadblocks

✓ Bring a different kind of patient insight, participation and engagement

✓ Improve disease understanding through PGD and ML/AI

✓ Increases the chance of regulatory drug approvals

✓ Digital solutions supporting BYOD to enhance patient centricity

✓ Empower the patient - reduce hospital visits and increase QoL

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Aparito capabilities

Clinician

Database

Sponsor

Patient

Patient Generated Outcome Data

Continuous Data

Digitalised Monitoring Process

Remote Disease Monitoring

Real Time data

Real Time Flags

Passive Data Capture

Paperless Data Capture

Medication Prompts

✓ Vastly improved understanding of diseases
✓ Increased chance of regulatory approval

✓ Better, cheaper & faster drug development
✓ Higher patient empowerment & quality of life

✓ More participants & engagement
✓ Lives Saved & Improved

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Other important features

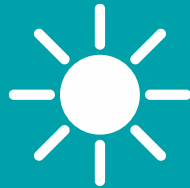Product enhancements, add ons and partners

RED FLAGS	CONNECTIVITY	THE WEATHER CHANNEL	DATA TRANSFER	APP ONLY	CHOICE OF CLOUD PROVIDER
Alerts for deteriorations & emergencies with ML/ AI	Medical consultations via video link e.g. Overseas patients	Cross referencing outcomes with temperature, humidity & pollen data e.g. Juvenile Arthritis	Full integration with Healthcare provider & sponsor's systems e.g. NHS medical records via EMIS	First Trial Q4'17	e.g. Microsoft Azure (NHS) e.g. IBM (Pivotal Studies) e.g. Client provider (GE Healthcare)

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Current trials

Co-developed in partnership with patients groups, clinicians and pharma-companies

NIEMANN PICK C

ACTELION

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Central Manchester NHS
University Hospitals
NHS Foundation Trust

JUVENILE IDIOPATHIC ARTHRITIS

The Newcastle Upon Tyne Hospitals NHS
NHS Foundation Trust

DUCHENNE MUSCULAR DYSTROPHY

DUCHENNE UK

The Newcastle Upon Tyne Hospitals NHS
NHS Foundation Trust

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

GAUCHER DISEASE

Shire

genzyme

Central Manchester NHS
University Hospitals
NHS Foundation Trust

MediScan

LATE ONSET TAY SACHS

NIH National Institutes of Health
Turning Discovery Into Health

To be deployed in Q2 2018

**PAEDIATRIC EPILEPSY**

GAUCHER DISEASE

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Patient interaction with mHealth technology

Areas of interest

- Mixed level of interaction – linked to study context (e.g. natural history vs exploratory)

- Prompted engagement (mPROs) = Good

- Independent reporting (Adverse Events and Visits) = Variable

- Uncovering data points that previously would go unrecorded

- Compliance to wearing a wristband for study data

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Patient interaction with mHealth technology

mPRO Completion Rates
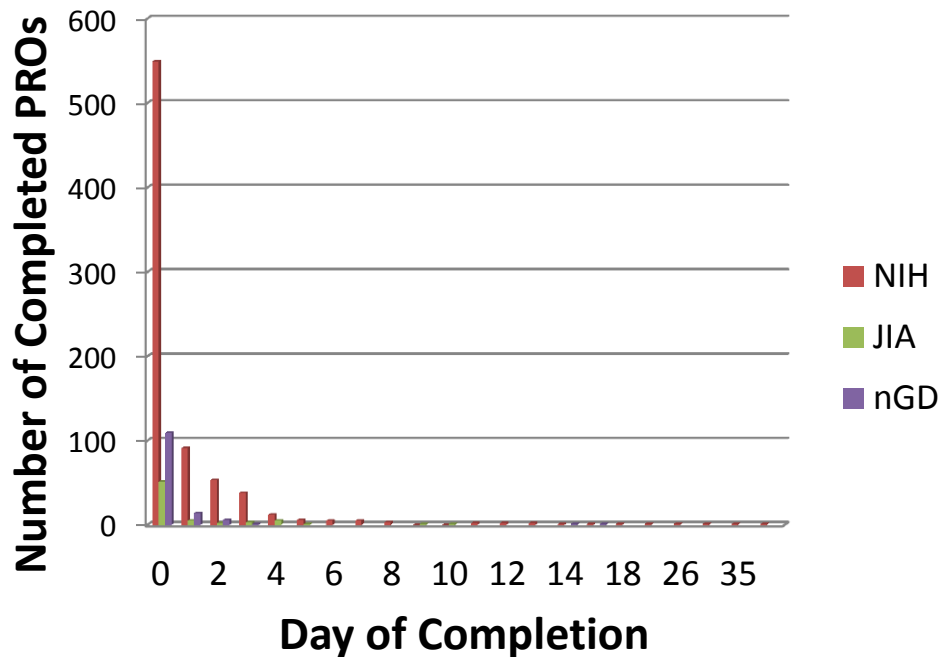
LOTS Patient Group (NIH) - ADULTS

71% Completion on day of issue
95% Completion rate within 3 Days

JIA Group (Newcastle NHS) – TEENAGERS

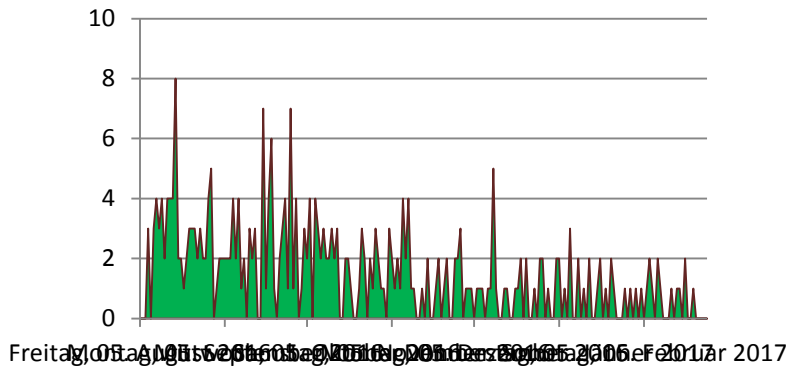74% Completion on day of issue
86% Completion rate within 3 Days

nGD Patient (Manchester Children's Hospital) - MIX

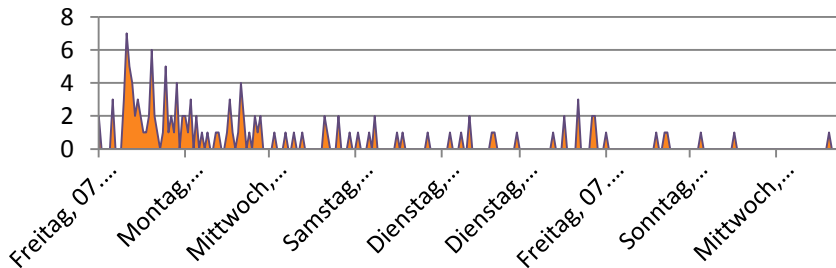83% Completion on day of issue
99% Completion rate within 3 Days

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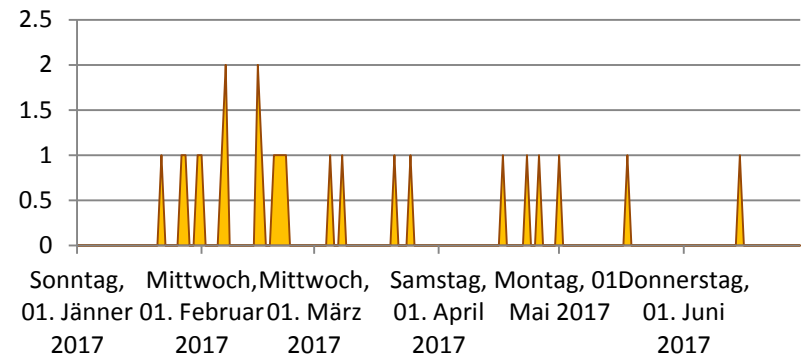# Patient interaction with mHealth technology

How does non-prompted engagement compare?

LOTS Patient Group (NIH)

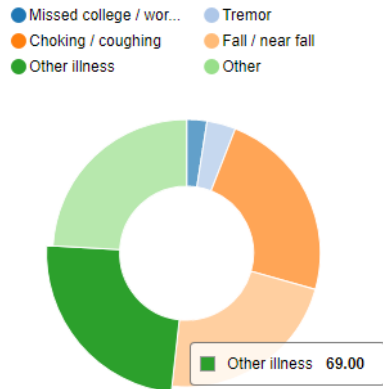**JIA Group (Newcastle NHS)**
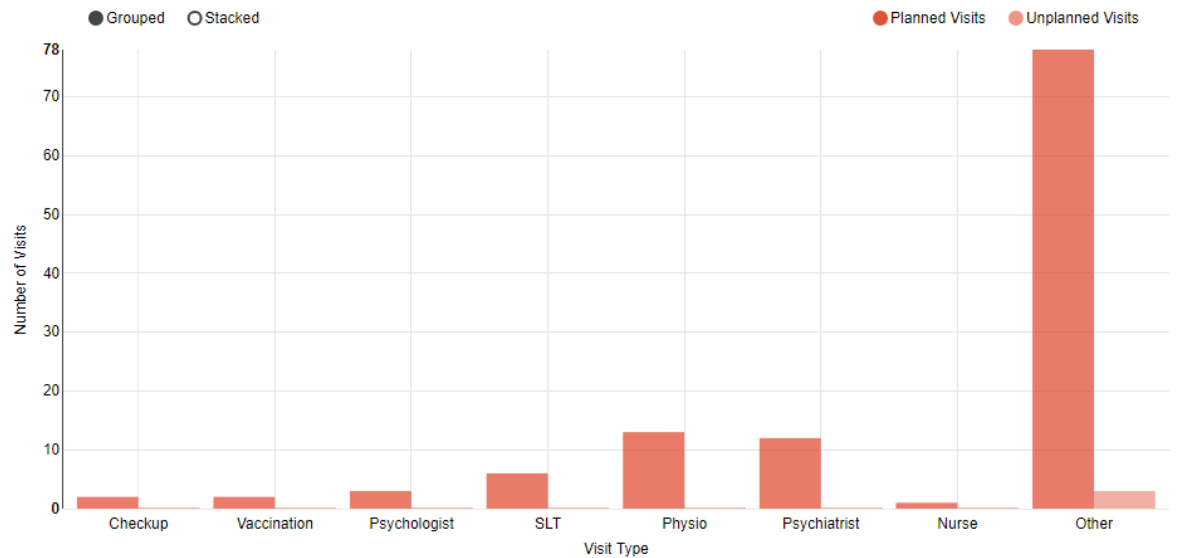

nGD Patient Group (Manchester Children's Hospital)

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Patient interaction with mHealth technology

Monitoring Adverse Events and Healthcare System Visits – The power of "Other"

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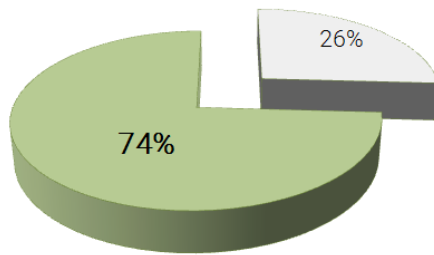
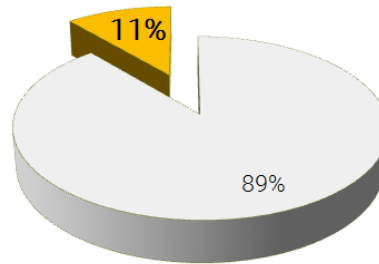# Patient interaction with mHealth technology

How engaged are patients with wearable devices?

LOTS Patient Group (NIH) – ADULTS

26%
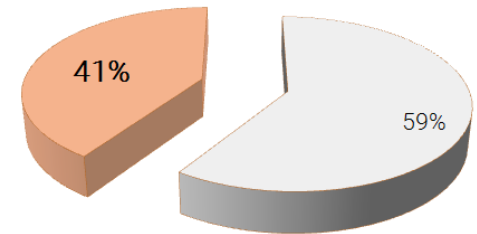
74%

Maximum Patient Engagement 99.59%
Minimum Patient Engagement 49.79%

JIA Group (Newcastle NHS) – TEENAGERS

11%

89%

Maximum Patient Engagement 41.47%
Minimum Patient Engagement 0.39%

nGD Patient Group - MIX

41%

59%

Maximum Patient Engagement 61.53%
Minimum Patient Engagement 11.53%

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Patient interaction with mHealth technology

How engaged are patients with wearable devices?

Factors Influencing the Adoption of Smart Wearable Devices

Apurva Adapa, Fiona Fui-Hoon Nah, Richard H. Hall, Keng Siau & Samuel N. Smith

📄 Full Article   🖼 Figures & data   📰 References   66 Citations   📊 Metrics   🖨 Reprints & Permissions   **Get access**

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ABSTRACT

This paper examined factors associated with the adoption of smart wearable devices. More specifically, this research explored the contributing and inhibiting factors that influence the adoption of wearable devices through in-depth interviews. The laddering approach was used in the interviews to identify not only the factors but also their relationships to underlying values. The wearable devices examined were a Smart Glass (Google Glass) and a Smart Watch (Sony Smart Watch 3). Two user groups, college students and working professionals, participated in the study. After the participants had the opportunity to try out each of the two devices, the factors that were most important in deciding whether to adopt or not to adopt the device were laddered. For the smart glasses, the most frequently mentioned factor was look-and-feel. For the smart watch, the availability of fitness apps was a key factor influencing adoption. In addition, factors which were linked to image, a personal value, were particularly important across both the student and working groups. This research provides support for the usefulness of the laddering approach to data collection and analysis, and provides some insight into key design criteria to better fit users' needs and interests.

Operational Challenges of Supporting Patients

Operational challenges

What are the issues with supporting patients in the wild?

- Wearables are easily lost or damaged. This creates logistical and cost challenges

- Wearables will need to be re-synchronized for a number of reasons

- Provision needs to be made for lost or damaged devices

- Supporting patients via conventional, unattended channels is inappropriate

- Not all patients are *"tech savvy"* (<u>patients </u>not users)

- Maintaining high levels of patient confidentiality requires clinical site co-operation

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What is the learning from all this?

Is there value in mHealth technology?

1. Design endpoints **with** patients

2. Simple to use, pre-configured technology is a must to support patient engagement

3. Engagement with wearable technology varies, more *"bling"* will likely see higher compliance

4. Patient "Activation" with HCP is essential

5. Understand the support commitment needed to keep patients engaged

6. The regulatory landscape is not likely to change – embrace it

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