MELANOMA UK

Data: How to collect it safely, what to use it for & why: the Melanoma UK digital registry

UK MELANOMA PATIENT CONFERENCE, BIRMINGHAM

SATURDAY 16TH JUNE 2017

vitaccess

Melanoma UK digital registry: introductions, roles and thanks

Study co-developer

Patient advocacy

- Gillian Nuttall, Founder and CEO
- Di Cannon, Director

Study sponsor

Joint academic leads

- Prof. Theresa Wiseman
- Dr James Larkin

Study co-developer

Healthcare research company, Oxford

- Dr Mark Larkin, Founder and Director
- Jon Spinage, Director of Technology

+ **Patients**

Today’s topics

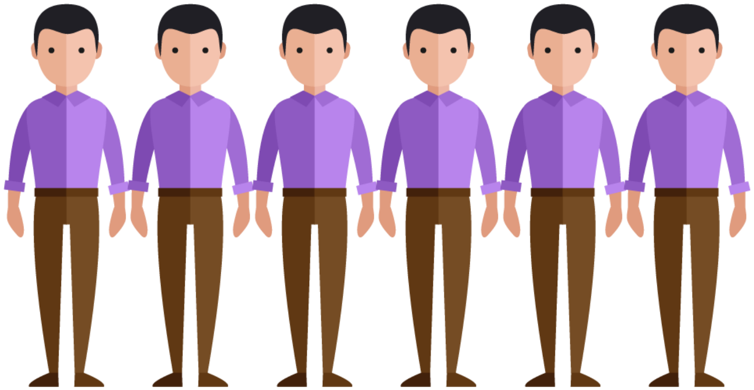
1. Introduction:
    - Why collect real-world data?
    - What to use it for?
    - How to collect it safely?
2. Case study: the Melanoma UK digital registry
3. Registry app: design and wireframes
4. Feedback: help us tailor <u>your</u> app
5. Q&A

Introduction

Why?

Efficacy (RCTs) vs. effectiveness (real-world)

Efficacy



Patient benefit and harm in experimental and closely monitored research studied, normally RCTs

Effectiveness

Patient benefit and harm when the technology is actually applied in everyday practice

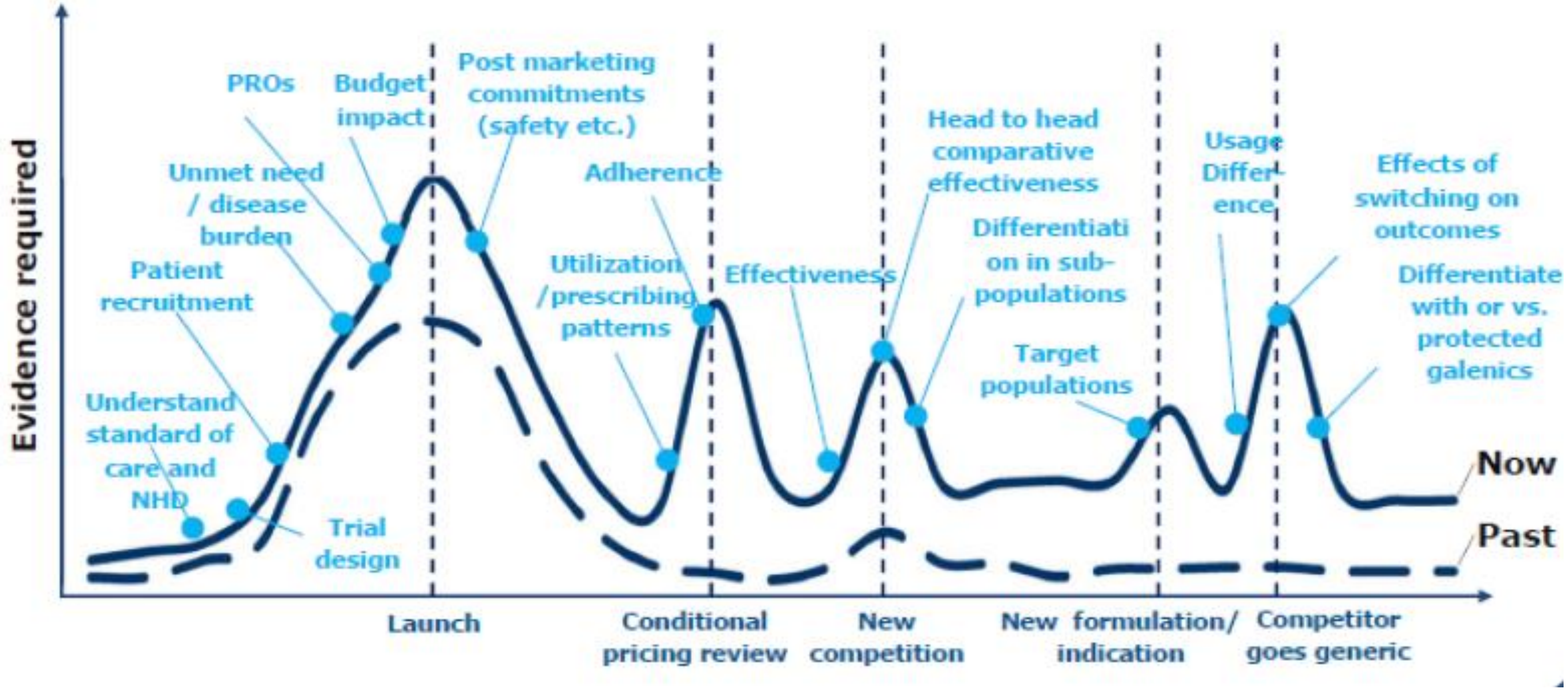
What?

Multiple stakeholders use RWE throughout product lifecycle

Development

Growth phase

Mature phase



How?

Protection of participants and academic rigor

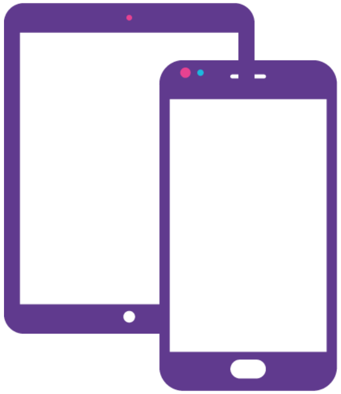
- Participative development
- Study protocol
- Academic oversight
- Ethics approval
- Participant information briefing and informed consent
- Independent scientific executive board (SEB)

…creating a dataset to improve care

Case study: the Melanoma UK digital registry

Overview of registry platform

Screening, informed consent, app installation



Tools and information to help you manage your condition

Questionnaires about how you feel

Research portal (aggregated data)

- Industry subscriptions
- Free to non-commercial researchers e.g.:

Data collection can help improve care

Data domains

- Demographics
- Lifestyle and exercise
- Previous and current treatments
- Quality of life
- Symptoms and adverse events
- Health resource utilisation

Research questions

- Impact of treatments?
- Treatment patterns?
- Equity of care?
- Quality of life?

Improving care

Mobile app: design and wireframes

Mobile app: wireframes

Feedback: help us tailor your app

Participative development: help us tailor the registry app

- Please help us rate the range of features that we have built in to help you manage your condition:

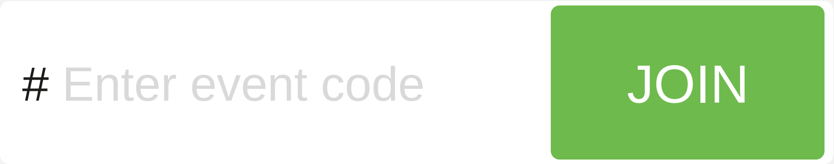
Slido

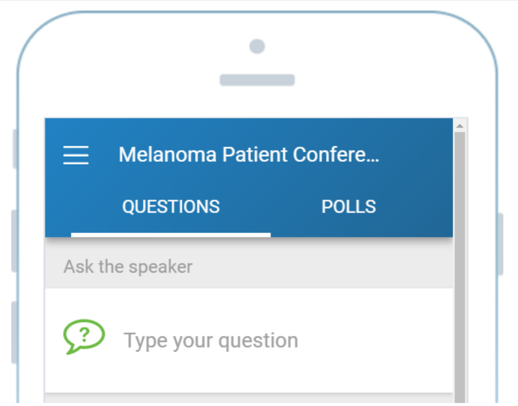
On your smartphone go to

slido.com

Enter event code:

#MPCUK





Wireframe feedback

We’re now going to switch over to the Slido display while you vote on each feature.

Q&A

Contacts

If you have any thoughts about this project we would love to hear from you:

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THANK YOU

MELANOMA UK

Fighting Melanoma Together

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