



The role of innovation: Apps & tools for chronic pain management

Active Citizenship Network
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Brussels



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Director
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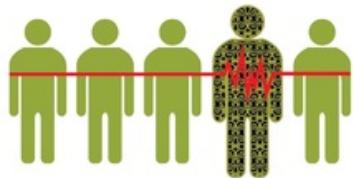




About PatientView

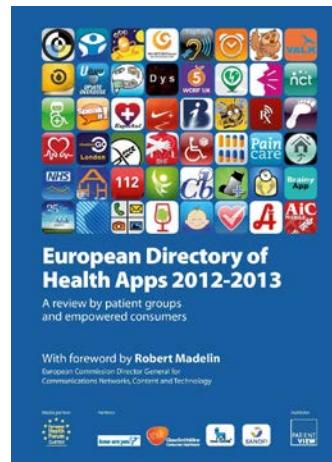
- UK-based research, consulting and publishing company
- Collects and analyses the viewpoints of thousands of patient groups (and their members) worldwide – since 2000
- Has the capacity to reach out to 120,000 patient organisations worldwide, covering over 1,000 health specialties.

Surveys, reports, white papers, directories, toolkits...



Benchmarking the patient movement—the global perspective (2nd edition)

- A global survey of the views of 1000-plus international, national, regional and local patient groups
- Provides a self-assessment of patient-group effectiveness worldwide in 2014
- Compared also with the results of the first such benchmarking exercise in 2012



European Directory of Health Apps 2012-2013

A review by patient groups and empowered consumers

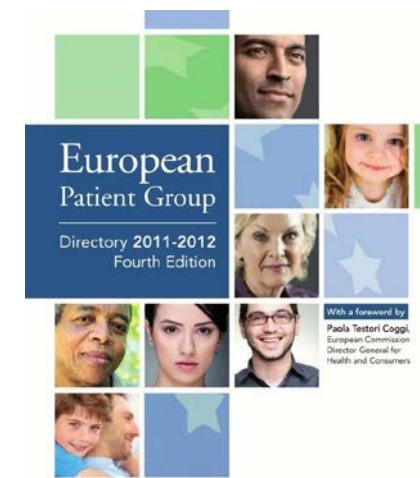
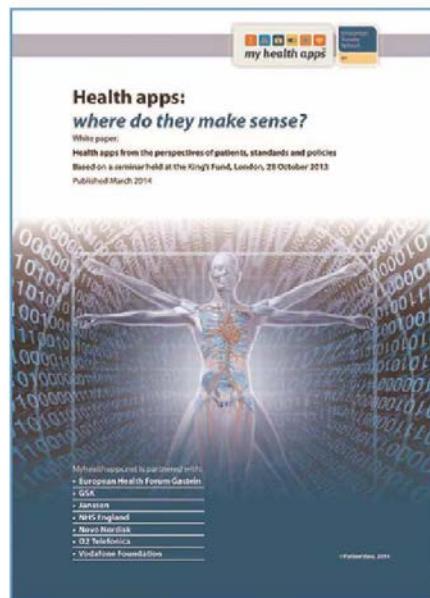
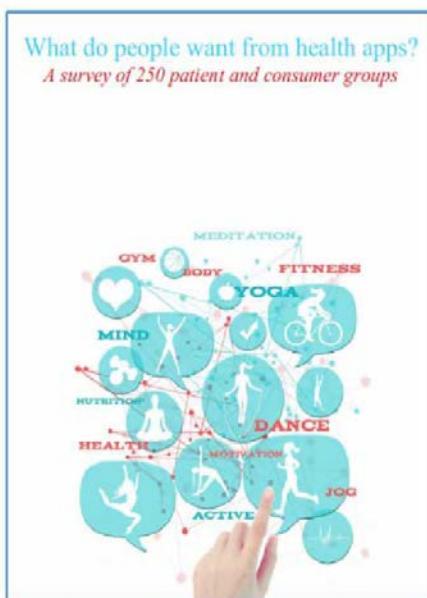
With foreword by Robert Madelin
European Commission Director General for
Communications Networks, Content and Technology



The Corporate Reputation of Pharma in Europe 2013—the patient perspective



A survey of the views of 500 patient groups from Europe on the corporate reputation of the pharma industry in Europe and 33 of its leading multinational pharma companies





The unavoidable logic of health apps

- Healthcare systems are in crisis, chiefly because chronic illness is on the rise as populations age
- Policymakers realise that without greater patient empowerment and self-care, healthcare systems will no longer be sustainable
- People living with chronic disease/pain manage their condition alone, on average, more than 99% of the time (Stanford University research)



Why do we need quality health apps?

- Health apps help the public and patients provide continuity of self-care during illness
- Health apps support self-management of health and wellbeing generally, not just the primary illness
- Health apps inform, bringing health information to the public and patients 24/7
- Health apps even can take a little pressure off time-stressed clinicians

health apps today - the good news



- Smartphones are now used even by some of the **more vulnerable and hard-to-reach sections of the population**
- Today, among the **100,000 health apps** on the market are many that can help people cope with a huge range of health issues—from diet and exercise, to monitoring their glucose levels or managing their medication
- People who download apps can be supplied with **continuous, up-to-date services by those tools**
- The services (information, practical facilities, and support) can **often be free**



why apps can help patients and carers

Apps can promote self-care by providing:

- round-the-clock support to patients and the public
- when and where they need it

Right support-right time



Step by step practical support



Right tools, right time



Disease awareness



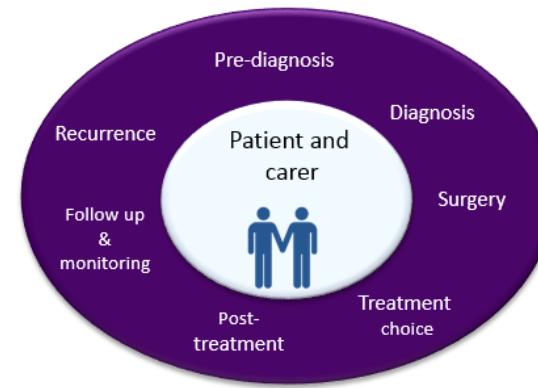
Treatment



Step by step emotional support



Breaking down isolation



Palliative care and end of life



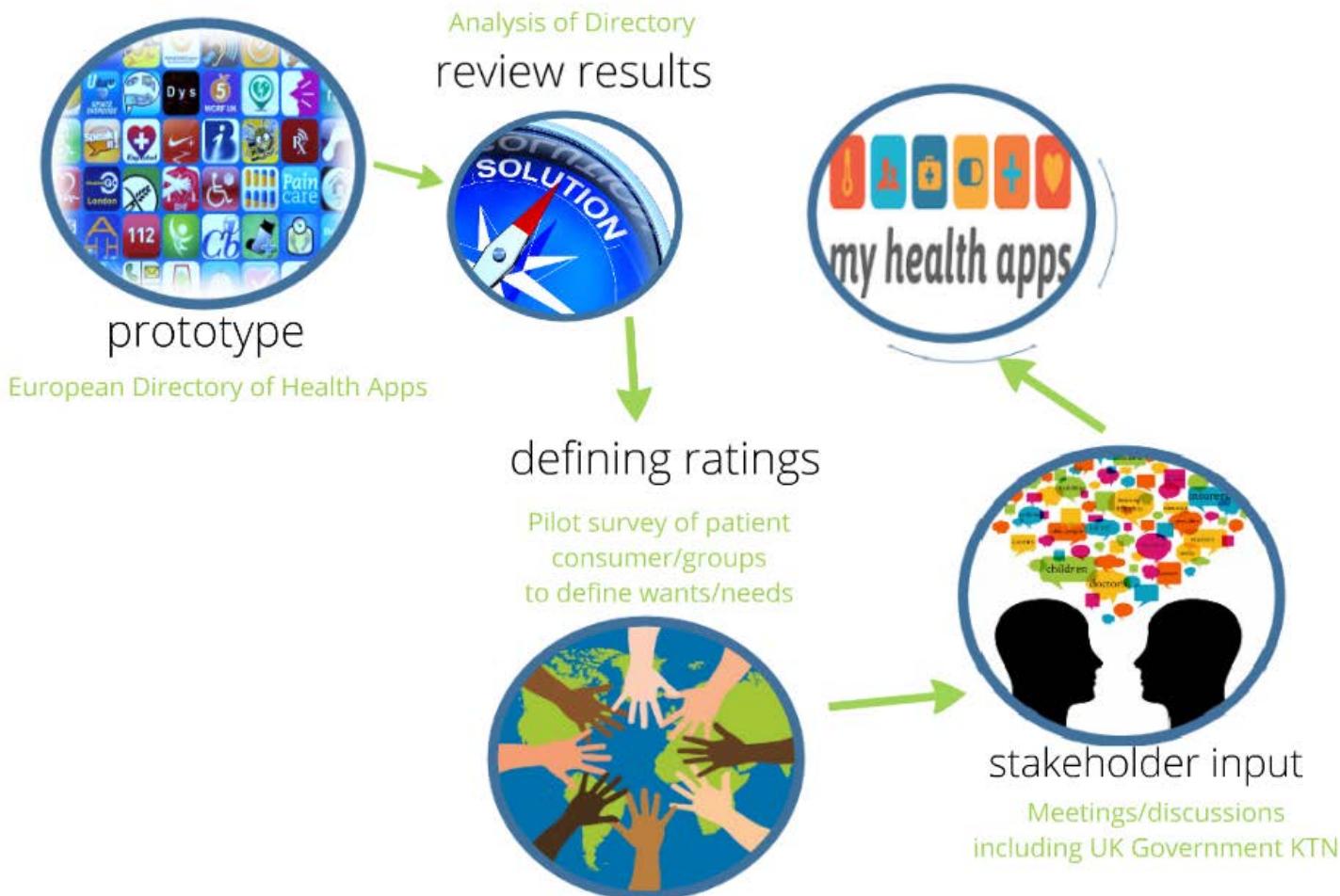


health apps today - still a gamble

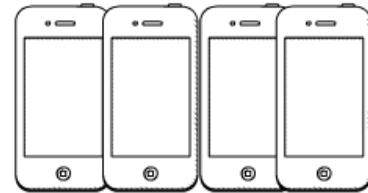


- The number of health apps available is currently huge—so great, that **informed choice is hard**
- Health apps **vary widely in quality and reliability**
- **Lack of clarity** as to whether health apps produce **positive outcomes**
- Accessibility of apps—**cost, technical problems, ease of use on smartphones**
- Fears about **data privacy**
- Issues of **transparency** about who has developed and financed the health apps

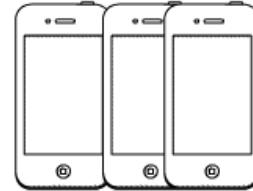
METHODOLOGY: over 3 years



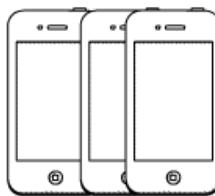
What patients and the public want from their health apps



Apps that make me feel more in control of my condition, 35.2%



Apps that are easy to use, 25.6%



Apps that are trustworthy, 25.1%



Apps that allow me to network with other people like me, or people who understand me, 11.2%



Apps that I can use regularly, 2.6%



Search Health Apps



Browse by Category



Bones and Muscles



Breathing and Lungs

Heart,
Circulation
and BloodMe and My
DoctorMental
HealthNervous
System and
BrainSexual
HealthStaying
HealthyStomach,
Bowel and
ContinenceSupport for
Senses,
Mobility and
LearningOther Long-
term
Conditions

Welcome to myhealthapps.net

myhealthapps.net brings together the world's favourite healthcare apps – tried and tested by people like you.

[More information →](#)

How Hearts Are Won



All the apps on this site have won recommendations from patients.

Our heart ratings give you an easy way to compare between the apps chosen for this site.

[More information →](#)

Top Chart



App of the Day

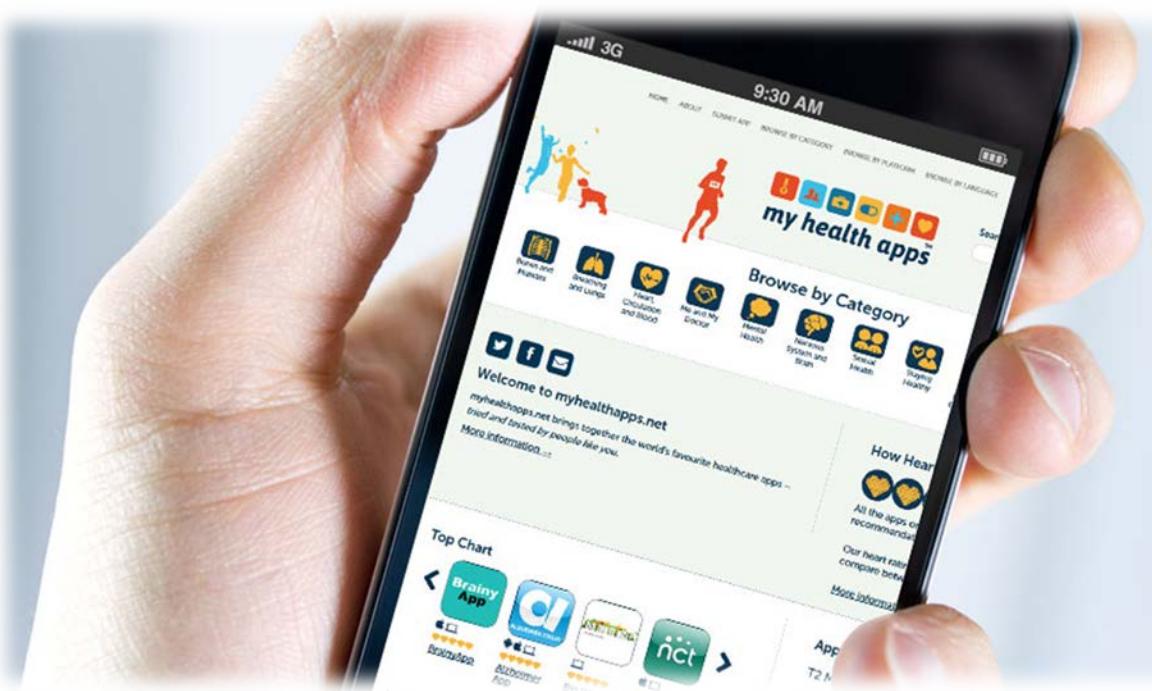
Parkinsons

Multi-stakeholder partnerships are key...



OUR PARTNERS

Pharma	<ul style="list-style-type: none">● GSK● Janssen● Novo Nordisk
Mobile operators	<ul style="list-style-type: none">● Telefonica● Vodafone Foundation (development phase)
<i>Non-commercial:</i>	
Media partners	<ul style="list-style-type: none">● European Health Forum Gastein
Government	<ul style="list-style-type: none">● NHS England (Health Apps Library)● Knowledge Transfer Network (UK)
Network and alliances	<ul style="list-style-type: none">● European Connected Health Alliance● Health 2.0● Mobile World Capital (tbc)● GARI (Global Accessibility Reporting Initiative – Mobile Manufacturers' Forum)



Where we are today...

- Over 400 apps
- Covering 150+ health specialties
- Apps in 50 languages (52 in Italian)
- Reviews by over 550 patient organisations worldwide

Wider context of chronic pain apps

- Nearly 500 ‘pain’ apps listed on Google Play
- Difficult to calculate on Apple App Store:
 - IMS Health Institute Report (October 2013) assessed all 43,000+ apps classified as ‘health apps’ on iTunes App Store and found that only 16,275 apps were directly related to patient health and treatment, and were of very variable quality and utility – so how are the public and patients to know how to find the ones they need and which ones to trust?

How sites like myhealthapps.net aim to help

17 apps on pain or chronic pain-related factors....



CatchMyPain

developed by Sanovation AG; Software Evolution and Architecture Lab (SEAL) Gruppe, Instituts für Informatik, Universität Zürich

Available in English / French / German / Spanish

Cost: Free

"An app that acts as a pain diary. I've found it to be incredibly useful in tracking possible cycles, and in remembering important days of pain (and possible causes). I'm finding it to be an invaluable resource. You can rate your pain, do colour-coded mapping on a human form to mark out where your pain is, and its severity, and detail specific things going on. They've also included a way now to send that information to your physician(s), if you so choose. When you've completed entries, it will chart them, so you are able to detect, for example, if a new medication is helping or not, or if a stressful event caused more damage than you would hope." Reviewer: Living With Fibromyalgia - Online Support Group, USA

<http://bit.ly/1edoHmy>

Developer:	Sanovation AG; Software Evolution and Architecture Lab (SEAL) Gruppe, Instituts für Informatik, Universität Zürich (Based in Switzerland) http://www.sanovation.com/
Funder:	Förderagentur für Innovation des Bundes, Kommission für Technologie und Innovation (KTI), Switzerland; Hasler Stiftung, Switzerland
Medical Adviser:	Klinikien Valens, Klinik für Rheumatologie und internistische Rehabilitation, Universität Zürich, Switzerland

Pain apps on myhealthapps.net

17 apps on pain or chronic pain-related factors....



Phrase Board

developed by Eamonn and Ian LLC, USA

- Available in Arabic / English / French / German / Italian / Spanish / Swedish
- Cost: Free [in English language only; the other six available through in-app purchase]

Allows people who cannot speak to display some basic concepts to other people.

"The advantages: the app aims to allow an individual with a communication impairment to communicate their location, level and frequency of pain, to answer basic questions, and to make basic comments and requests. The person can also save custom comments that are more relevant to their own situation. The disadvantages: the app does not allow for voice output, so that any medical professional in attendance would need to be watching what the person is touching on the screen." **Patient group specialising in communication disability, Australia | PatientView survey, July-August 2012**

Developer: Eamonn and Ian LLC, USA (Based in United States) <http://www.eamonnandian.com>

Funder: Same as technical developer

Medical Adviser: Same as technical developer

Pain apps on myhealthapps.net

17 apps on pain or chronic pain-related factors....



Tip Share

developed by ConRadical LLC, USA

Available in English / Spanish

Cost: Free

Helps the user to manage joint pain from arthritis by reading advice and 'tips' from other people who are living with the condition.

*"People can use the app as a tool to network with others about the disease, and share ways they've found to manage their signs and symptoms. It's great. You can find out how to manage your arthritis joint pain from people like you. In this peer-to-peer arthritis community, the app gives you the opportunity to share your own arthritis tips about managing arthritis pain, rate other people's tips, and view tips from the Arthritis Foundation. It's a community of support, and a way to keep track of your health. " **Arthritis Foundation, USA** | PatientView survey, July-August 2012*

Developer: ConRadical LLC, USA (Based in United States) <http://www.conradical.net>

Funder: Arthritis Foundation [USA-based patient group specialising in arthritis]

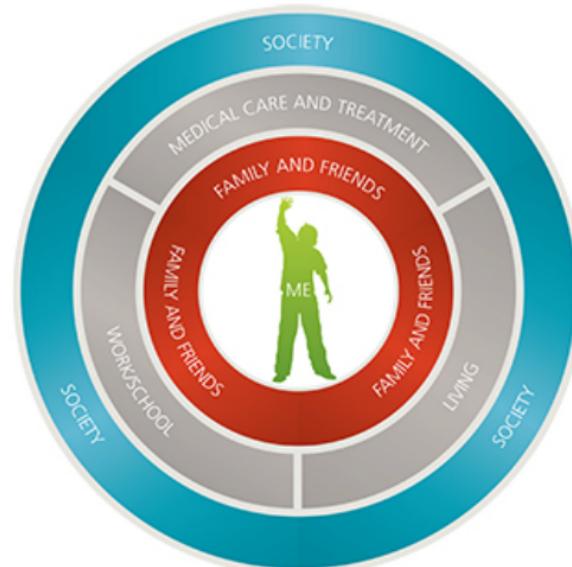
Medical Adviser: Arthritis Foundation [USA-based patient group specialising in arthritis]



Looking at all aspects of patient life

Focusing on the healthcare issues and challenges faced by patients/carers/consumers. For example:

- * mental health
- * physical health
- * lifestyle choices
- * financing personal healthcare
- * family and friends' support (psychosocial support)
- * medical care and treatment

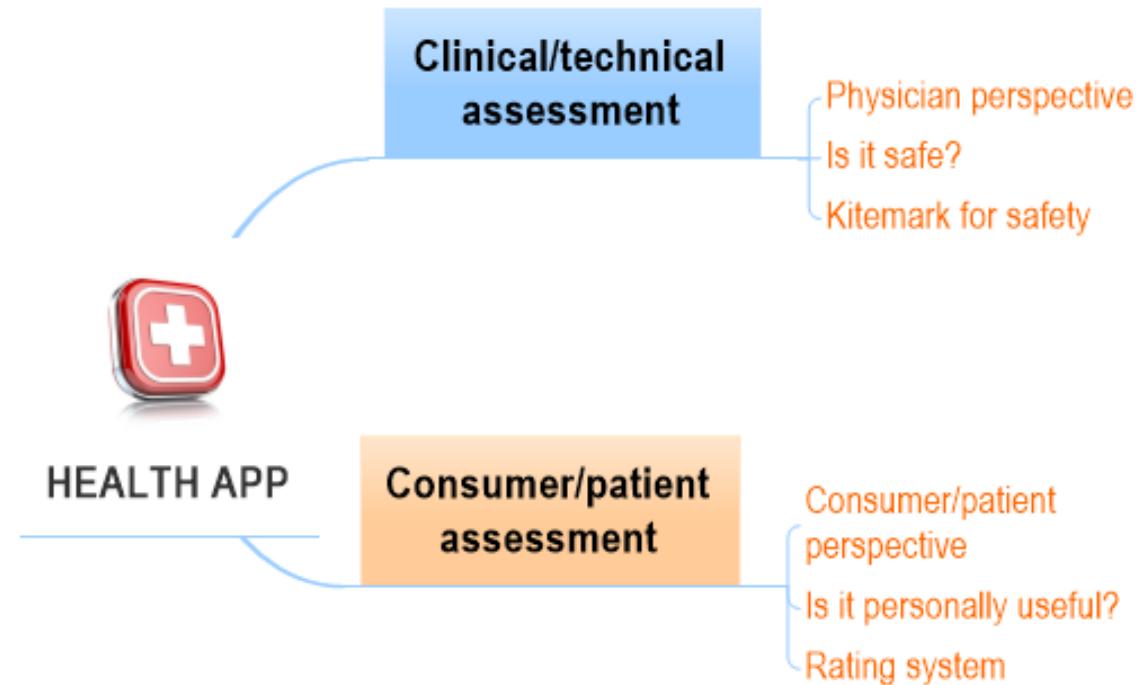




developing standards

The regulatory landscape is changing...

... as is the demand for high-quality apps



In future, app developers may need to secure a presence (gain approval) among many of the organisations involved with quality assessments of health apps



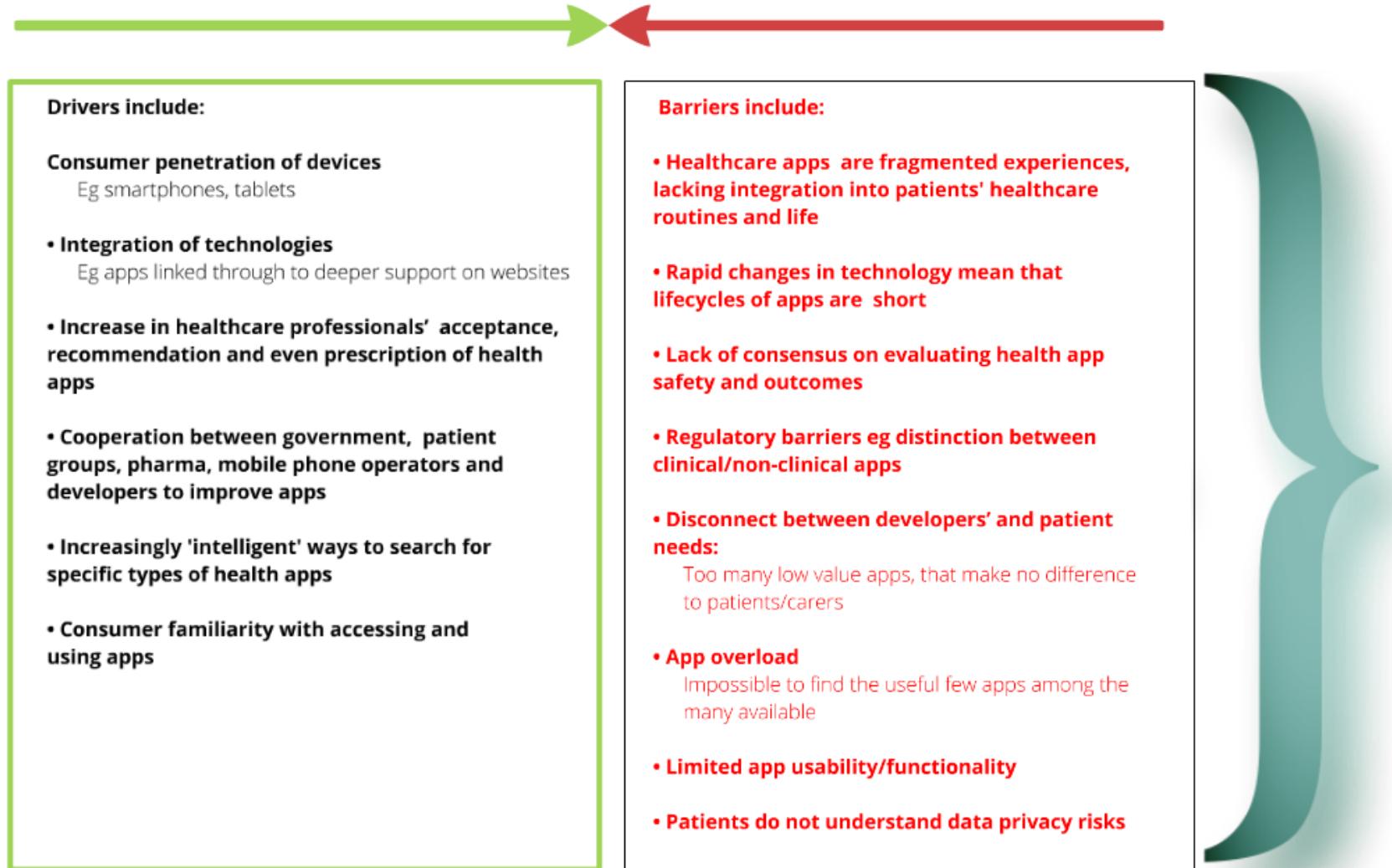
The importance of **transparency** is recognised in the European Commission Green Paper on mHealth (10 April 2014):

“Some initiatives focus more on the transparency of the information about reliable health apps like the first European Directory of Health Apps [myhealthapps.net].”

Myhealthapps.net gives information about and links to (where possible) the:

- App developer
- Funder
- Medical Adviser

Summary: where we are today



Key issues to be addressed

- **UNMET PATIENT NEEDS**
- **QUALITY AND STANDARDS OF APPS**
- **DATA SECURITY AND PRIVACY**
- **REGULATION**

Autumn 2014: The Commission is due to publish the responses to the public consultation on its mHealth Green Paper

Early 2015: The Commission is due to publish its proposals on the regulation of mHealth tools and devices, including apps

Our next steps



1 October 2014

at European Health Forum Gastein

- Launch of a print and online (free) toolkit for the public and patients to help them get the best from health apps but be aware of the pitfalls



12 November 2014, London

- A free collaborative workshop to connect patient and carer groups, policymakers, healthcare professionals, telecoms and mobile experts, and medical device experts with health developers.

- To help define 5 new important apps to be designed in response to patient unmet needs



my health apps™



THANK YOU

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