

# EPIS Digital Engagement Toolkit



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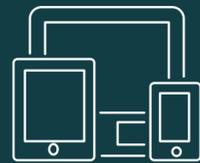
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# Introduction

At the European Patient Innovation Summit 2020 (EPIS 2020), patient leaders and advocates from across Europe connected to discuss digital engagement – how, within healthcare, we can harness the incredible power of digital channels and new technologies to improve patients’ lives and the healthcare services they use.

Participants voted on a series of recommendations for actions that four different stakeholder groups (patient organisations, healthcare professionals (HCPs), policy makers, and technology developers) should take to ensure that patients continue to benefit from digital engagement opportunities. You can find the top three recommendations for each stakeholder and voting results on pages 4 and 5.

Three key themes were identified:



**Advocating for simplified and standardised digital platforms**



**Improving digital health literacy**

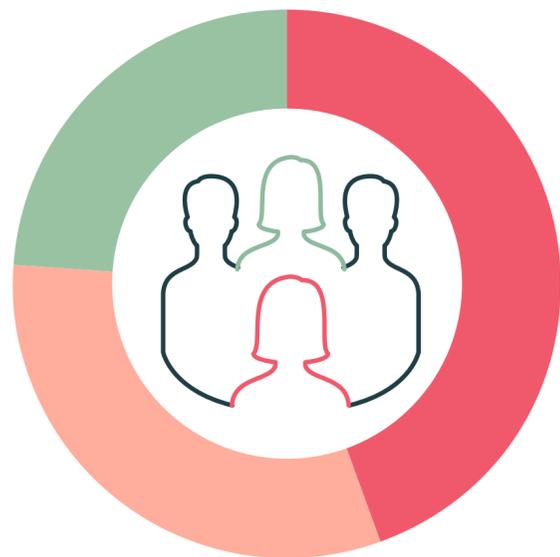


**Ensuring co-creation of digital health solutions**

This **EPIS Digital Engagement Toolkit** has been developed by the EPIS Steering Committee in order to help support EPIS participants with the local implementation of these key recommendations on digital engagement. In this Toolkit, you will find a series of three example advocacy plans summarising potential questions and actions to address them.

# Recommendations from the EPIS community (as voted on at EPIS 2020):

How can we ensure that patients continue to benefit from digital engagement opportunities?



Patient Organisations<sup>1</sup>

- 28%** **Create a national, digital patient platform** that is simple to use, and can be used for education, training, meetings, and online consultations with healthcare professionals
- 20%** **Educate patients on digital health literacy** including the use and benefits of digital health solutions
- 15%** **Make digital innovation a political and societal priority** that is centred around improving quality of life for patients, not technology companies and healthcare organisations



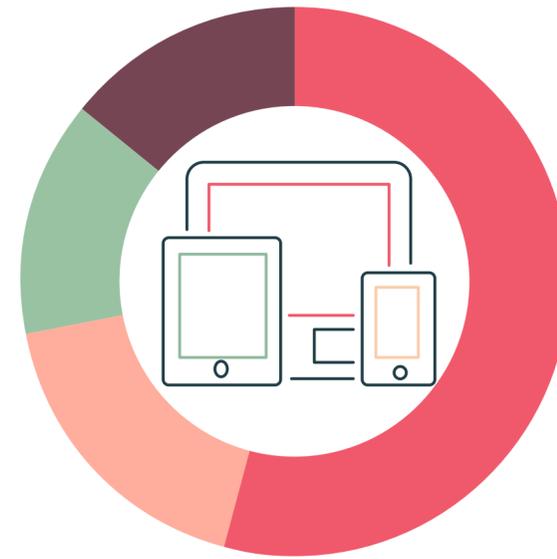
Health Professionals<sup>2</sup>

- 27%** **Implement standardised digital health platforms** used by both health professionals and patients (e.g. for teleconsultation, health records)
- 24%** **Help patients interact with health services/professionals digitally** by improving access, training and education for digital solutions
- 19%** **Humanise and adapt digital healthcare** so patients and health professionals are more comfortable using it



### Policy Makers<sup>3</sup>

- 31%** Provide a central digital health literacy educational tool which can be utilised by patient organisations, and distributed to patients and health professionals, so that they can better utilise existing tools
- 19%** Make it easier for patients to interact with their health professionals or health service directly
- 17%** Create one centralised national telemedicine system with virtual clinics



### Technology Developers<sup>4</sup>

- 43%** Co-create digital solutions with patients and health professionals from the early stages of development, to ensure optimal experience and accessibility
- 14%** Ensure the digital tool being developed is relevant to patients and is meeting a specific unmet need
- 11%** Establish clear objectives for the co-creation process from the onset and actively seek feedback from different stakeholders throughout the development process
- 11%** Create a legal framework which protects both patient communities and organisations, and data from projects

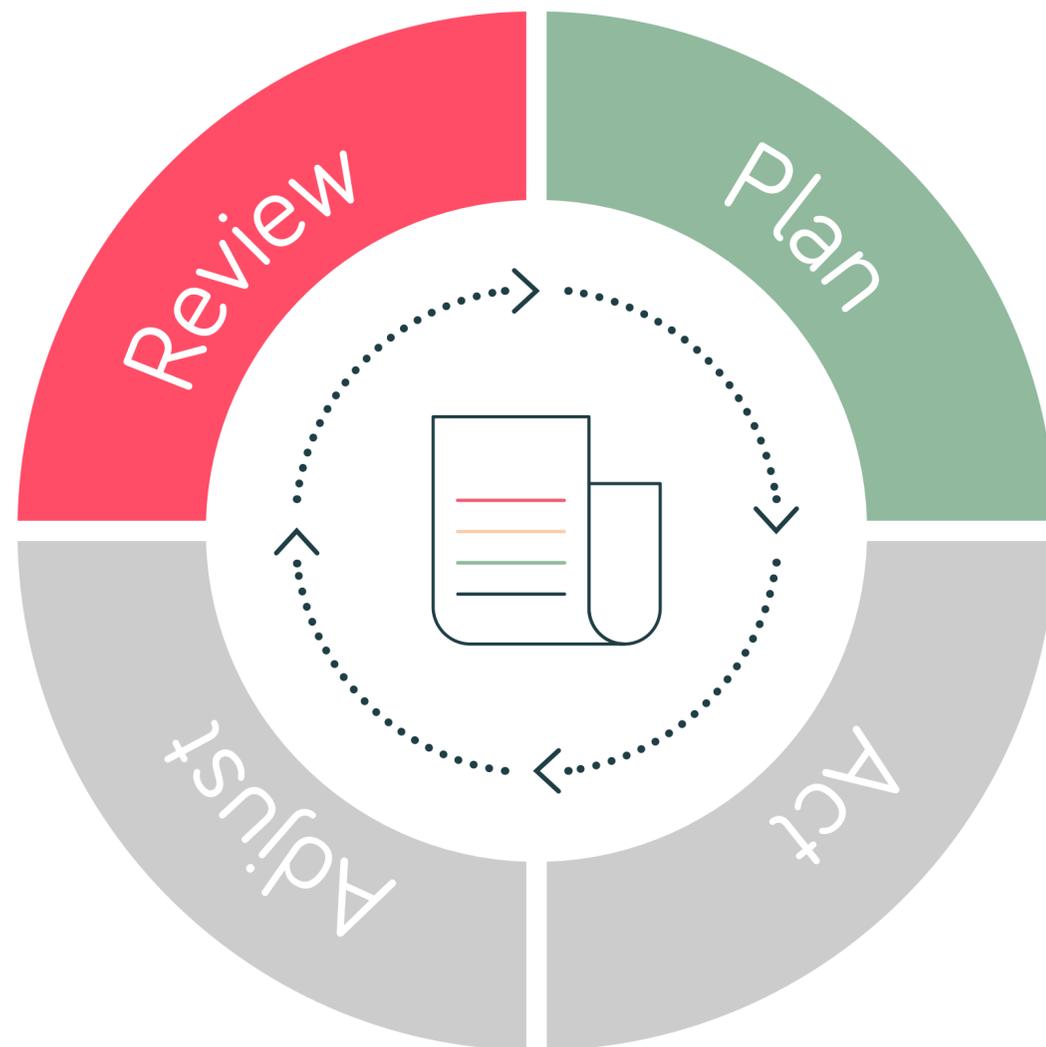
**Footnotes** **1.** The recommendations outlined for patient organisations represent the three recommendations that received the most votes from 149 patient community representatives participating in the voting during the EPIS 2020 Summit on the 5th November 2020. **2.** The recommendations outlined for health professionals represent the three recommendations that received the most votes from 144 patient community representatives participating in the voting during the EPIS 2020 Summit on the 5th November 2020. **3.** The recommendations outlined for policy makers represent the three recommendations that received the most votes from 145 patient community representatives participating in the voting during the EPIS 2020 Summit on the 5th November 2020. **4.** The recommendations outlined for technology developers represent the recommendations that received the most votes from 148 patient community representatives participating in the voting during the EPIS 2020 Summit on the 5th November 2020.

# How to use the Digital Engagement Toolkit



- Each example advocacy plan uses four steps: review, plan, act and adjust
- The plans show how the EPIS recommendations could be put into practice. Where recommendations are broad or more ambitious, these goals may need to be broken down into smaller steps
- Each section includes suggested questions to ask yourself at each step of the planning process as well as example actions. These are merely examples and it is good to remember that sometimes one well executed action may be better than implementing lots of different activities

# Using the example plans



## Step 1 Review:

### Conduct a situational analysis in your setting (e.g., disease area, geographical location)

This step is about understanding the current situation in the disease area you are working within, or within your local country/region. What exists/is happening currently with regards to the issue on which you have decided to focus, and any activities you could potentially take part in.

#### Key questions to consider:

- What evidence is available to provide insight

into the current situation and the scope of the problem faced in implementing change?

- What are the unmet patient/HCP needs regarding this issue?
- What solutions/efforts/tools/activities already exist?
- What challenges do you anticipate when addressing this issue?

## Step 2 Plan:

### Set the goals you want to achieve:

Set SMART<sup>1</sup> goals that are specific, measurable, achievable, relevant and time-based.

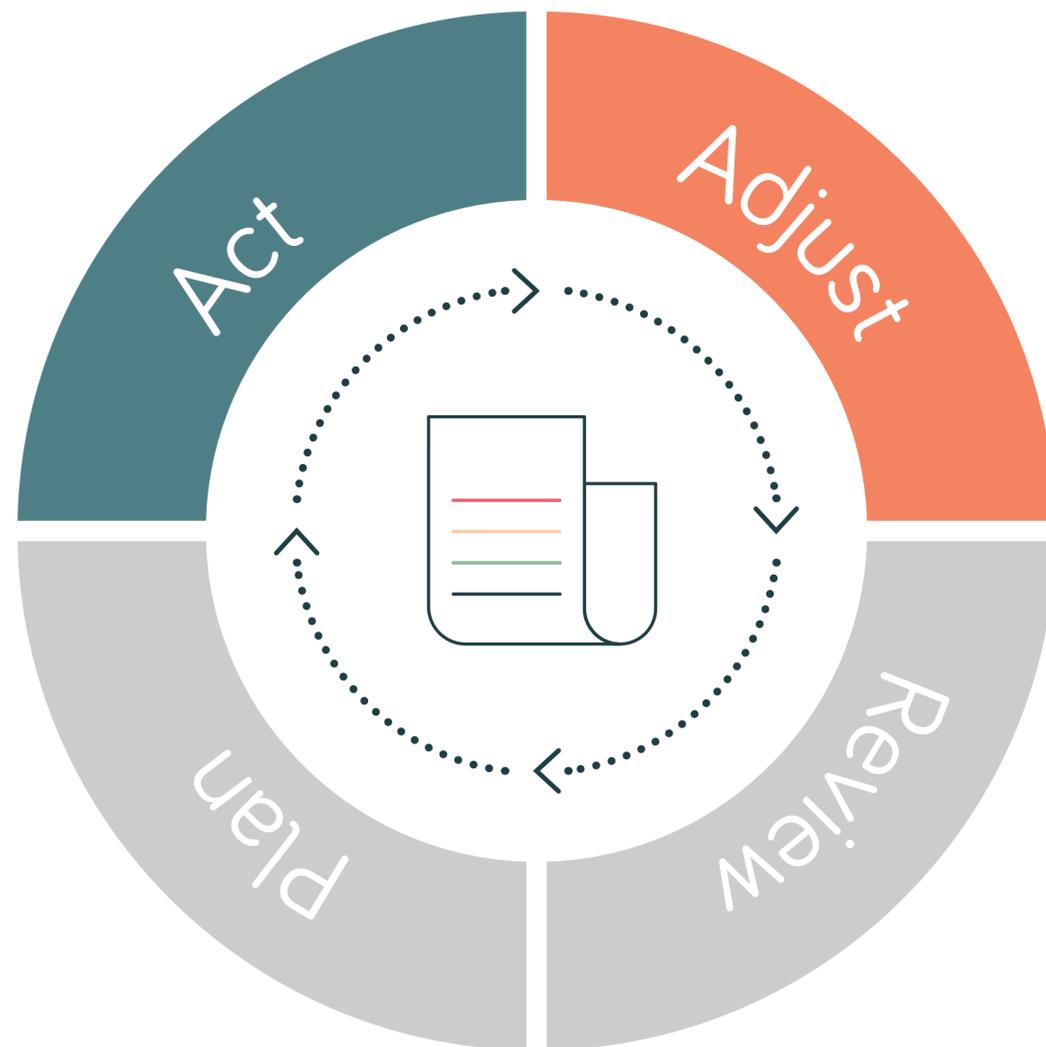
#### Key questions to consider:

- What is the priority area for action?
- What do you think is achievable in light of the situational analysis and your resources?
- Are your goals specific (simple, sensible, significant), measurable (meaningful, motivating),

achievable (agreed, attainable), relevant (reasonable, realistic and resourced, results-based) and time bound (time-based, time limited, time/cost limited, timely, time-sensitive)?

- Is the goal addressing the main challenge of patients/HCPs for this topic?
- What will be our key performance indicators (KPIs)?

# Using the example plans



## Step 3 Act:

### What do you need to do to achieve your goals? (including resources):

Set a 'roadmap' of the actions that will be conducted in order to reach the goal, along with potential timelines, and assess what is realistically achievable. Consider what is already in existence, as well as the financial and human resources that will be available to conduct the activities.

#### Key questions to consider:

- What are our critical success factors (i.e. organisational capacity, identification of key stakeholders in our country)?

- Do we need to build a coalition/alliance with other stakeholders?
- What unique role do we play as an organisation?
- What actions will ensure we achieve our goals?
- What is needed at an organisational level for this exercise to be successful?
- What opportunities can be leveraged to help ensure success?
- What resources, tools or assets already exist that can be used?

## Step 4 Adjust:

### Measure the success of your activities and refine

Review the initial goals that were set in the 'plan' phase and consider what metrics will help to measure the success of these goals (this works best when the metrics are decided before initiating any activities). Collect the data and analyse it, considering what the key learnings are, impact of the activities, and what could be done differently/improved.

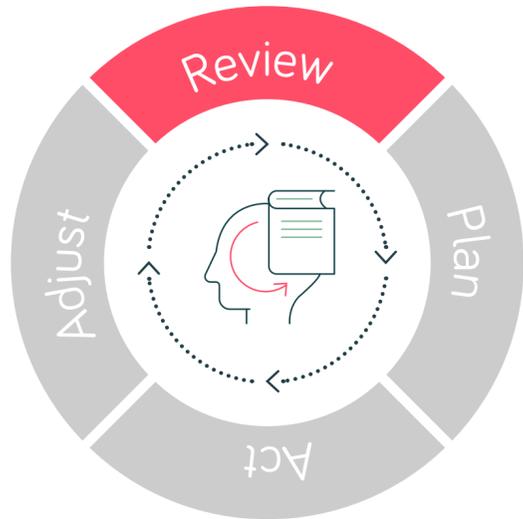
#### Key questions to consider:

- What data could show that we have achieved our goal?
- What have we learnt from this experience?
- Were there any barriers to being successful?
- What changes do we need to make to our plan?



# EXAMPLE 1:

## Advocating for simplified and standardised digital platforms



### Step 1 Review:

**Conduct a situational analysis in your setting (e.g., disease area, geographical location)**

#### Key questions to consider

- Is there already a digital health platform? How comprehensive is it? Does it address the key needs of patients?
- How do patients/HCPs currently engage with existing digital health platforms?
- Which stakeholders have an interest in expanding/building a digital health platform?

#### Potential actions\*

- Patient community survey to better understand needs on digital health platforms
- Map existing digital health platforms & mine publicly available user experience data
- Map & prioritise stakeholders interested in digital health platforms (e.g. policy makers, industry associations, technology providers/ developers)

### Notes:

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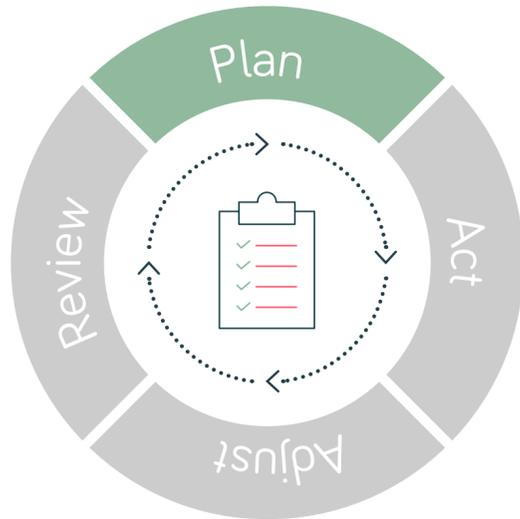
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\*Example actions are included for demonstration purposes only, this is not an extensive list that should be considered



# EXAMPLE 1:

## Advocating for simplified and standardised digital platforms



### Step 2 Plan:

#### Set the goals you want to achieve

##### Key questions to consider

- Do we need to carry out a multi-step initiative with short- medium- and long-term goals?
- What can be achieved in the short term?

##### Potential actions\*

- Set SMART goals. Project example: Improve simplicity of virtual platforms for HCP consultations in Sweden by mapping key

stakeholders and implementing an outreach programme to obtain expressions of interest in a call for action to modify and improve platforms within a six month timeframe. Meets SMART goals as project is: specific (provides a simple goal), measurable (can measure number of expressions of interest), achievable (would require limited resources), relevant (realistic for our organisation) and time bound (six month deadline)

- Set KPIs. E.g. target of 10 stakeholder expressions of interest or signatures on document calling for change around platforms

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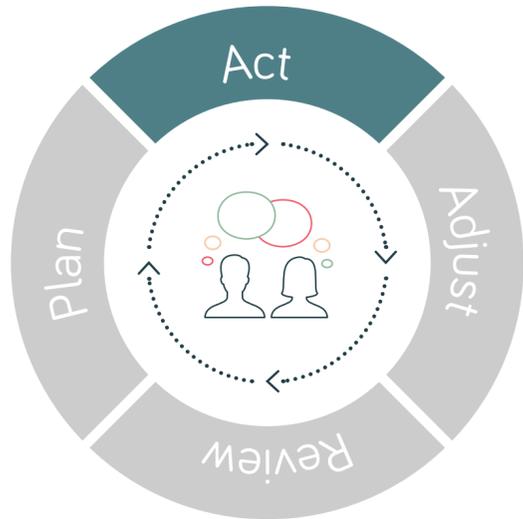
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# EXAMPLE 1:

## Advocating for simplified and standardised digital platforms



### Step 3 Act:

What do you need to do to achieve your goals? (including resources):

#### Key questions to consider

- How to approach potential partners to co-create/provide a patient perspective?
- How can we enable exchange between patients and developers of platforms?

#### Potential actions\*

- Create a roadmap of the activity (short and long term actions that need to be achieved over a timeline of critical points in the process)
- Conduct a survey on digital health platforms and publish results on

social media/share with media

- Create/share social media content on the challenges associated with digital health platforms
- Organise a roundtable event with key stakeholders (e.g. governmental representatives, developers). Resources for hosting meetings can be found [here](#)
- Join alliances/coalitions addressing similar goals or collaborate on other stakeholders' initiatives
- Brief a journalist for a feature article on innovation in digital health platforms. Resources on creating a press kit can be found [here](#)

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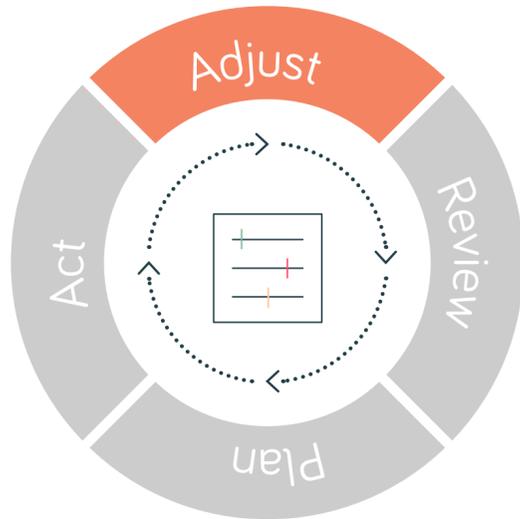
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# EXAMPLE 1:

## Advocating for simplified and standardised digital platforms



### Step 4 Adjust:

Measure the success of your activities and refine

#### Key questions to consider

- Has there been an increase in patient representative engagement in digital platform initiatives?
- Are guidelines/policies addressing patients' needs for digital health platforms?
- Is the patient/HCP perspective on/satisfaction of digital health platforms changing?

#### Example measurement tools / metrics

- Patient community survey before/after activities to determine status of digital platforms locally
- Number of digital health platforms co-developed and endorsed by the patient community
- Number of stakeholders referring to the patient perspective

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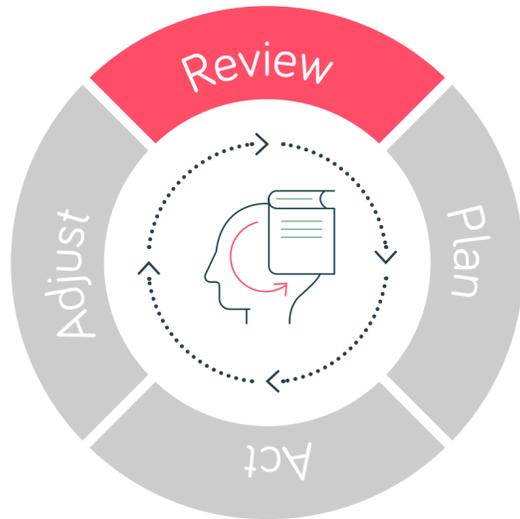
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# EXAMPLE 2: Improving digital health literacy



## Step 1 Review:

**Conduct a situational analysis in your setting (e.g., disease area, geographical location)**

### Key questions to consider

- Where are the gaps in digital health literacy? (i.e. patients, HCPs etc.)
- Do we know the extent of digital health illiteracy in the target audience?
- Are there existing digital health literacy initiatives that can be adapted?
- Is there a connection to overall digital literacy?

- Who are the key stakeholders addressing digital health literacy? Through which activities?

### Potential actions\*

- Literature review regarding digital health literacy
- Desk research to identify activities that have previously been undertaken/are ongoing on digital health literacy, resources at a global level that could be used locally
- Qualitative research – interviews with patients, HCPs or surveys

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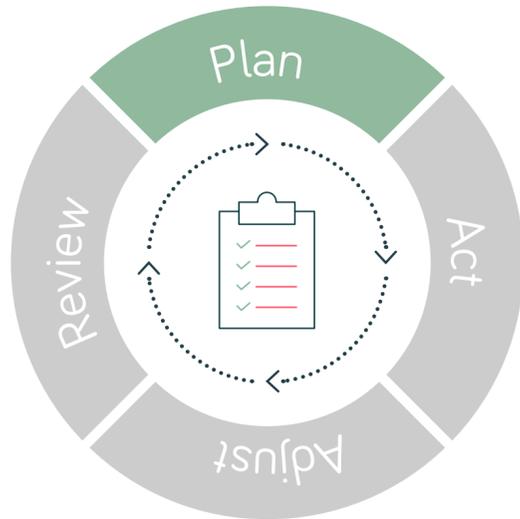


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# EXAMPLE 2: Improving digital health literacy



## Step 2 Plan:

### Set the goals you want to achieve

#### Key questions to consider

- What are the most important gaps in digital literacy that were identified in the situational analysis?

#### Potential actions\*

- Set SMART goals. Project example: Improve the digital health literacy of elderly patients by creating an easy-to-understand guide to using digital technologies to seek information relating to health

that is distributed by email to the organisation’s membership over the next year. Project meets SMART goals as it is: specific (provides a simple goal), measurable (can measure number of email opens, materials distributed), achievable (would require relatively few resources to create materials), relevant (realistic goal for our organisation) and time bound (one year deadline)

- Set KPIs. E.g. target of 20% open rate of email

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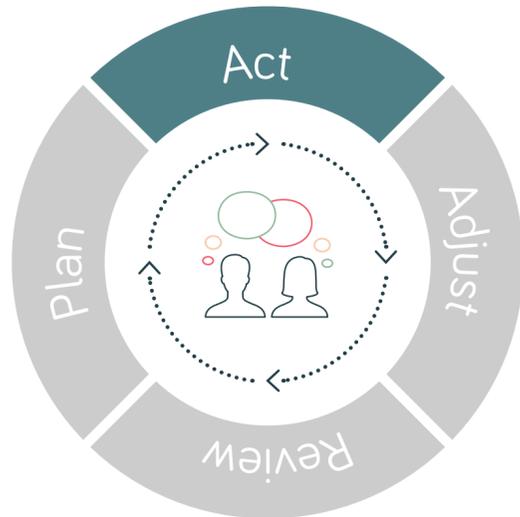


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# EXAMPLE 2: Improving digital health literacy



## Step 3 Act:

**What do you need to do to achieve your goals? (including resources):**

### Key questions to consider

- How best to target different audiences? How should we change our messaging based on the audience?
- What does good/bad look like?
- What useful tools have been identified?
- Where is there opportunity to partner with other stakeholders to provide input?

### Potential actions\*

- Create a roadmap of the activity (short and long term actions that need to be achieved over a timeline of critical points in the process)
- Create a platform with accurate, educational tools on digital literacy

or share on current platforms (social media, website). E.g.

[Asthma UK digital health resources](#)

- Create an interactive lexicon in local language
- Provide input on the patient perspective of language being used in digital tools – guidance on how to best describe things to improve use
- Reach out to HCPs and other interested stakeholders to assess opportunities to form alliances, or join coalitions addressing similar goals e.g. [Data Saves Lives](#)
- Hold a virtual educational event (e.g. [European Society of Cardiology \(ESC\) Digital Health Week](#) educated HCPs on digital solutions in cardiovascular disease)

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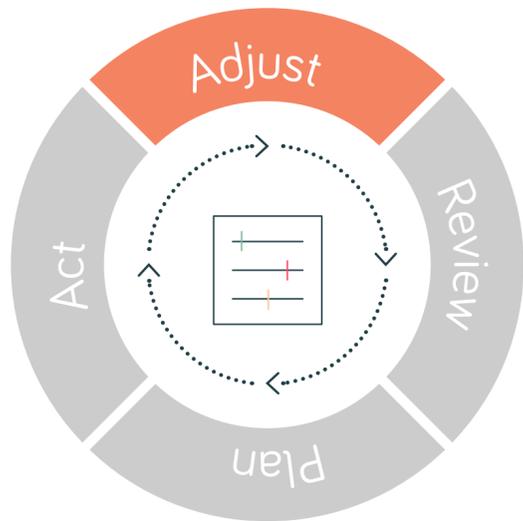


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# EXAMPLE 2: Improving digital health literacy



## Step 4 Adjust:

Measure the success of your activities and refine

### Key questions to consider

- Has there been a measurable increase in digital health literacy amongst our audience (HCPs, patients etc.)?
- What specific elements / gaps are there regarding digital health literacy that still aren't understood?

### Example measurement tools / metrics

- Survey to test people's digital health literacy (before/after activities)
- Number of downloads of resources/tools
- Number of visits to webpages with resources/tool
- Social media engagement with content (likes, shares, comments)
- Number of attendees at virtual events

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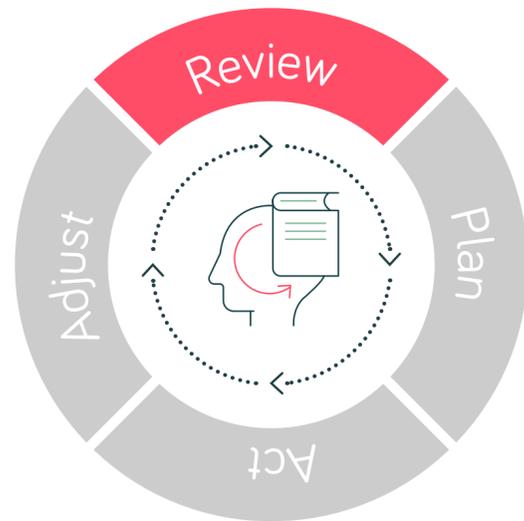
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# EXAMPLE 3: Ensuring co-creation of digital health solutions



## Step 1 Review:

**Conduct a situational analysis in your setting (e.g., disease area, geographical location)**

### Key questions to consider

- What evidence do you have that engaging patients in the development of digital health solutions is beneficial?
- Are there any technology developers in your country interested in engaging with patients in the co-creation of solutions?
- Is there a local digital health ecosystem that you can get involved with?
- Which stakeholders are supportive of patient inclusion (e.g. policy makers, funders etc.)?

### Potential actions\*

- Desk research of tools available or in development for patients/ HCPs, and any activities, conferences or hackathons to get involved in
- Interview local HCPs and patients to understand what tools are in use
- Reach out to local technology companies to understand what tools are in development, and potential for collaboration

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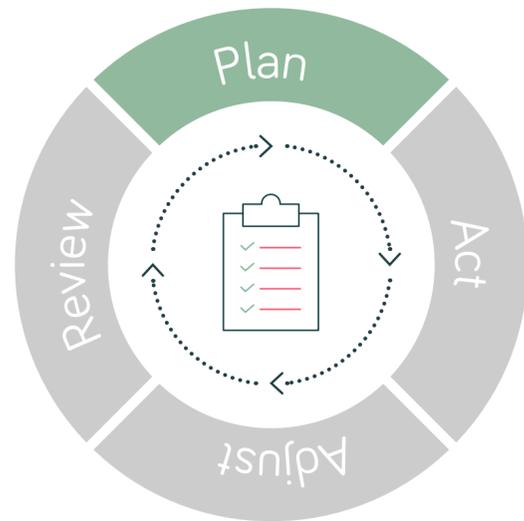
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# EXAMPLE 3: Ensuring co-creation of digital health solutions



## Step 2 Plan:

### Set the goals you want to achieve

#### Key questions to consider

- What are the principles our organisation should align to for co-creation?

#### Potential actions\*

- Set SMART goals. Project example: Increase our organisation's voice in the co-creation of solutions by mapping and reaching out to 10 technology organisations across the next year and introducing our organisation. Project meets SMART goals as it is: specific (provides

a simple goal), measurable (can measure outreach, success of outreach), achievable (would require limited resources to map organisations and conduct outreach), relevant (realistic goal for our organisation) and time bound (one year deadline)

- Set KPIs – e.g. target of contact with 10 technology organisations and initial meetings held with at least two organisations on digital health solutions
- Outline key principles for how we would like to work with our partners. For a useful example of how this might look, see [here](#) from the MS Society (UK)

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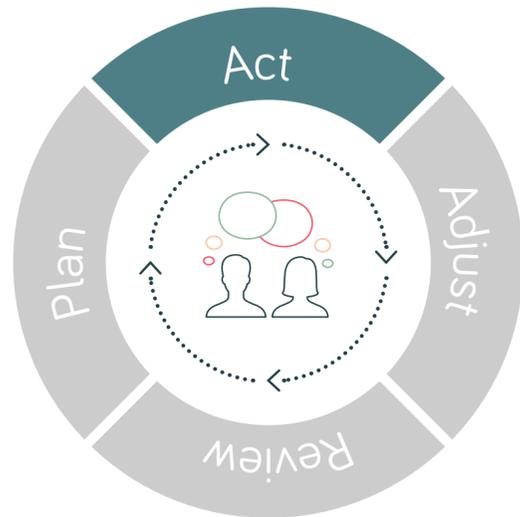
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# EXAMPLE 3: Ensuring co-creation of digital health solutions



## Step 3 Act:

**What do you need to do to achieve your goals? (including resources):**

### Key questions to consider

- Which stakeholders are we already in touch with? Where do we need to further build relationships?
- Who should be our spokesperson - engaging with developers, or providing the patient voice?
- How should we approach potential partners among the technology community to co-create/provide a patient perspective?
- How should we co-create the digital health solution together?
- How do we ensure the digital health solution is used by patients and HCPs?
- Where can we be proactive in our approach?

### Potential actions\*

- Create a roadmap of the activity (short and long term actions that

need to be achieved over a timeline of critical points in the process)

- Map developers to approach and reach out to introduce organisation and offer collaboration. Don't wait to be invited – be proactive (e.g. see [Patient Innovation](#), a platform for patients and those who care about them to share and access useful solutions for different diseases)
- Publish report highlighting needs around digital health solutions – e.g. MS Society: [Improving care for people with MS: the potential of data and technology](#)
- Conduct a survey to understand best used tools by HCPs/patients. Share survey results on social media, use as tool to further engage with developers
- Participate in hackathons or attend digital conferences
- Useful website to visit: [European Connected Health Alliance](#)

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# Resources

## Creating an advocacy plan

### Useful tools:

- [ShareForRare](#): Toolkit for patient advocacy
- [World Health Organisation \(WHO\)](#): Stop the global epidemic of chronic disease: A practical guide to successful advocacy

### Examples of advocacy plans:

- [European Patients' Forum \(EPF\)](#): Digital tools for patient empowerment and person centered care engagement roadmap
- [MS Society](#): Accelerating innovation for people living with MS

## Other useful resources

### Educational programmes/resources:

- [WECAN virtual academy](#): features key educational resources for patient advocates in the three pillars of Advocacy Tools & Skills, Healthcare Systems, Policy & Access and Research & Data.
- [EURORDIS Digital School on Social & Digital Media](#): a free online programme composed of webinars and e-learning courses.
- [Guide to GDPR](#)
- [Information on the European Health Data Space](#)

### Resources for hosting meetings:

- [High Impact Virtual Engagements \(HIVE\) webinar series](#): This webinar mini-series aims to help patient organisations organise impactful virtual events. During the webinars, Elena Balestra, European Patients' Forum (EPF) and Chi Pakarinen from Patient Focused Medicines Development (PFMD), interview Sean Baulk, from events company GCO, on 33 key questions for organising a virtual event for the patient community.
- [Information on BarCamp meetings](#): A BarCamp is a style of meeting where the content of the meeting is decided by those in attendance. People come together to discuss a broad overarching topic and then propose content to be discussed within this.

# Resources

## Creating a press/media kit

Reaching out to media can be an important way to share your messages with a particular audience. Firstly, determine the appropriate publications for your message/audience and carry out research to find the health/digital/technology editors at your target media outlets. After this, collate a press kit with the necessary tools to reach out to journalists.

### A press kit would normally have the following elements:

- **Press release:** this should be included only if you have news to communicate, it is not a prerequisite for engaging with media. When creating a press release, give information in descending order of importance, i.e. the first paragraph provides information on the who, what, why, and when of the news and the subsequent paragraphs provide more details and quotes from spokespeople from your organisation. Consider what your 'hook' is for media – what will make them want to write about this story? Keep the headline short, ensure quotes are meaningful, and consider using sub-bullets to convey your key messages.
- **Backgrounders:** these are factsheets that provide journalists with extra details/facts/statistics about the topic being discussed, e.g. digital (e-health) health literacy – what is it and why does it need to be improved? Journalists need visuals and statistics to increase audience engagement with articles – consider providing them with useful visuals to convey the topic, or results from a survey that support your key message.
- **Spokesperson biographies:** have an expert on hand or representative of your organisation who can be interviewed by journalists and/or provide a quote. Make sure:
  - Their picture and biographical details are available for journalists to use.
  - They have been briefed appropriately prior to reaching out to media, and are prepared for things like the interview being cancelled at the last minute, having to conduct a virtual interview with media etc.
- **Case studies:** have a case study that is relevant to the topic you are speaking about and country/location. Consider what makes the case study interesting – e.g. is there an interesting or unusual angle to the story? For a patient case study, could you put forward a patient's family members to share their point of view?
- **Q&A:** this is a back up resource to have to hand in case the journalist asks any questions that you/your spokesperson need to respond to.
- **Visual library:** have relevant images for journalists to use to illustrate their stories. For example, a logo of your organisation, pictures of patients, experts, or screen grabs of any important documents.



