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|---|---|
| **Project Title** | AI-based long-term health risk evaluation for driving behaviour change strategies in children and youth |
| **Project Acronym** | SmartCHANGE |
| **Grant Agreement No.** | 101080965 |
| **Project Start Date:** | 1 May 2023 |
| **Project Duration:** | 48 months |
| **Project Website:** | https://www.smart-change.eu/ |

# Participatory Research Protocol

| | |
|---|---|
| **Work Package** | **3** |
| **Lead Partner** | VuMC |
| **Contributing Author(s)(Partner)** | Claudia Dictus (VuMC)<br>Teatske Altenburg (VuMC)<br>Mai Chin A Paw (VuMC) |
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| **Version** | 1.0 DRAFT NOT YET APPROVED BY EUROPEAN COMMISSION |

**Dissemination Level**

| | |
|---|---|
| **X** | PU – Public, fully open |
| | SEN – Sensitive, limited under the conditions of the Grant Agreement |
| | Classified R-UE/EU-R – EU RESTRICTED under the Commission Decision No2015/444 |
| | Classified C-UE/EU-C – EU CONFIDENTIAL under the Commission Decision No2015/444 |
| | Classified S-UE/EU-S – EU SECRET under the Commission Decision No2015/444 |

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| **Abstract:** | This document provides information on the participatory research trajectory. It contains an overview of the development of the two applications in all four study sites within the three relevant stakeholder groups (healthcare practitioners, families and adolescents). It provides a framework for the research as well as an initial timeline, research goals and suggested activities to address them. |
| **Keyword List:** | Artificial Intelligence & Decision support, chronic diseases, risk assessment, children, youth, long-term risk prediction, chronic NCD, behaviour change, artificial intelligence, federated learning, explainable AI, robustness, bias, participatory design, proof-of-concept study |
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# Versioning history

| *Version* | *Date* | *Author(s)* | *Notes &/or Reason* |
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| **0.1** | 27/07/2023 | Claudia Dictus (VuMC)<br><br>Teatske Altenburg (VuMC) | TOC and V0.1 |
| **0.2** | 20/09/2023 | Claudia Dictus (VuMC)<br><br>Teatske Altenburg (VuMC) | Feedback relevant consortium partners- adjustments to framework, timeline and activities. |
| **0.3** | 25/09/2023 | Claudia Dictus (VuMC)<br><br>Teatske Altenburg (VuMC) | Internal feedback, adjustment of timeline, reordering of content. |
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### Quality Control (peer & quality reviewing)

| *Version* | *Date* | *Name (Organisation)* | *Role & Scope* |
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| **0.3** | 28/09/2023 | Maroje Sorić (ULJ) | Peer review / Quality check |
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| **0.3** | 02/10/20203 | Elena Mancuso (ENG) | Peer review / Quality check |

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# Executive summary

*This document provides the protocol for carrying out the participatory design that will engage users in the creation of the two applications that make use of the risk prediction models. This protocol outlines the practicalities regarding which type of research takes place in what location, the research timeline, the specific research goals and how they will be achieved through a rough outline of suggested research activities. Each country will conduct research with healthcare practitioners for the development of the web-app, and each will work with at least one of the following: families with children (under the age of 10) or adolescents (age 11-14). A minimum of one facilitator is needed for each of the stakeholder groups, to be available for at least the full year of 202. A research framework has been developed for this project making use of theories and practices within the fields of participatory research and co-design. The four phases of the research are as follows: phase 1 partnership building; phase 2 explore; phase 3 define; phase 4 generate and improve. Each phase is structured according to the design diamond structures of convergence and divergence to allow creativity as well as prioritization. Each phase has two to three specific research aims, which are further specified into actionable goals that can be addressed in individual participatory sessions. The phases are covered at different rates by different stakeholder groups and within a different number of sessions. Recommendations for the number and frequency of sessions are given, though the exact details are subject to discussion in collaboration with participants. The 23 distinct research goals are approached in slightly different ways for each stakeholder group, where the session guides containing suggestions for the organization of the session and activities that could be carried out are unique to each group. Within each session the specific outputs and how these will be used in design are also described. This protocol will be employed and improved throughout an ongoing process of training, discussion and feedback among the facilitators of each study site to allow for responsiveness to the needs of participants and the local context.*

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# List of abbreviations

| *Abbreviation* | *Definition* |
|---|---|
| AI | Artificial Intelligence |
| HCP | Healthcare Practitioners |

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# 1 Introduction

This project involves participatory research methods with three different stakeholder groups: healthcare practitioners, families of young children (under the age of 10), and adolescents (age 12-14). As many definitions and terms exist within the umbrella of participatory research and participatory design, it is important to note what is meant by the term in this document. Though participatory research as an umbrella term has many meanings, Montreuil et al distinguish between participatory *methods* which involve comprehensively engaging participants in research activities with the end goal of collecting data from them, and participatory *research* where participants are equal agents involved in making key decisions related to the research itself [1]. Various other terms exist, including co-design, co-creation and co-production, and exact definitions of these vary depending on the discipline and context. As a result of the preferences and practical limitations of health and design partners involved in the project, this protocol predominantly outlines the use of participatory methods to collect data throughout the research process with different stakeholder groups. The notable exception relates to the research conducted with adolescents which is intended to take a participatory research approach, where participants are co-researchers involved in designing and carrying out their own research and design. The underlying ethos of the research project in both instances involves an understanding that healthcare practitioners, families and adolescents (hereafter: stakeholders) are seen as experts of their own experience equal to any expert involved in the research and design process.

The aim of this protocol is to guide the diverse participatory research with the different stakeholder groups. Tables 1 and 2 below show overviews of stakeholder groups engaged in each country, the sample sizes and some details relating to the number of stakeholders and frequency of meetings for each group. The following sections will outline how this protocol is intended to be used, the underlying theoretical framework, the timeline and finally general guidance on the proposed research activities.

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*Table 1: Partners and Sample Size per Application*

| Stakeholder Group | Consortium partners | Group set-up | Total sample per country |
|---|---|---|---|
| **Healthcare practitioners** | VUmc, JAMK, Uporto, ULJ ENG | 2-4 groups of 6-8 healthcare practitioners | 18-32 |
| **Families** | ULJ, Uporto CCARE | 2-4 groups of 6-8 parents (+ their children) | 18-32 |
| **Adolescents** | VUmc, JAMK, ULJ, CCARE | 2 groups of 6-8 adolescents | 8-16 |

*Table 2: Facilitation Information per Stakeholder Group*

| Health partner | Stakeholder group | Minimum no. of Facilitators | Frequency of co-creation sessions |
|---|---|---|---|
| **VUmc** | Youth Health Care Practitioners (HCP) | 1 | Monthly |
| | Adolescents (age 12) | 2 (strongly advised) | Weekly |
| **JAMK** | School nurses (HCP) | 1 | Monthly |
| | Adolescents (age 11 and age 14) | 2 (strongly advised) | Weekly |
| **ULJ** | Multidisciplinary teams (HCP) | 1 | Monthly |
| | Families (children 6-10) | 2 (if with children) | Bi-weekly |

| | | | |
|---|---|---|---|
| **Uporto** | Pediatricians (HCP) | 1 | Monthly |
| | Families (children 6-10) | 2<br><br>(if with children) | Bi-weekly |

## 1.1 How to use this protocol

Given that this project takes place in four distinct countries and among multiple distinct stakeholder groups, this protocol does not aim to provide full detailed scripts for research activities as this would prevent the necessary responsiveness and contextual sensitivity required to successfully work across these differences. Additionally, as the content of a session depends on the previous session, details cannot be provided in advance. As such, the sessions described in this protocol need further preparation by the facilitators, which will be addressed during the training (in November 2023) and facilitator meetings (which will be scheduled throughout the process). This protocol contains the theoretical framework and initial timeline for activities as well as suggestions for how these activities align with the research goals and with the design timeline. It is an evolving document that will be expanded over time to add in more details. As such, suggested activities, numbers of sessions and the nature of the research itself (i.e., participatory approach vs. participatory methods) may be subject to change in the future. The current outline contains the minimum number of sessions and the most ideal timeline for their completion.

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# 2 Research Approach

## 2.1 Theoretical Framework

The theoretical framework for this protocol is derived from a combination of existing frameworks such as Te Morenga et al.'s Participatory Design Cycle and the British Design Council's Double Diamond Innovation Framework, with some contributions from Sander & Stapper's co-creation framework [2-4]. The strengths of these frameworks, such as the cyclical structure that allows for reflexive and iterative work in the Te Morenga framework and the content guidance of the double-diamond, were combined to create a set of research phases visualized in Figure 1 below. Phase 1 is an overarching phase focused on building research partnerships with stakeholders, which is an ongoing process. Phase 2, the explore phase, focuses on understanding the context and needs of stakeholders. Phase 3 is the define phase which aims to create a consensus on an understanding of the underlying problem for which in the fourth and final Generate and Improve phase, a solution will be designed. More detailed explanations of the phases can be seen in Table 3 below.

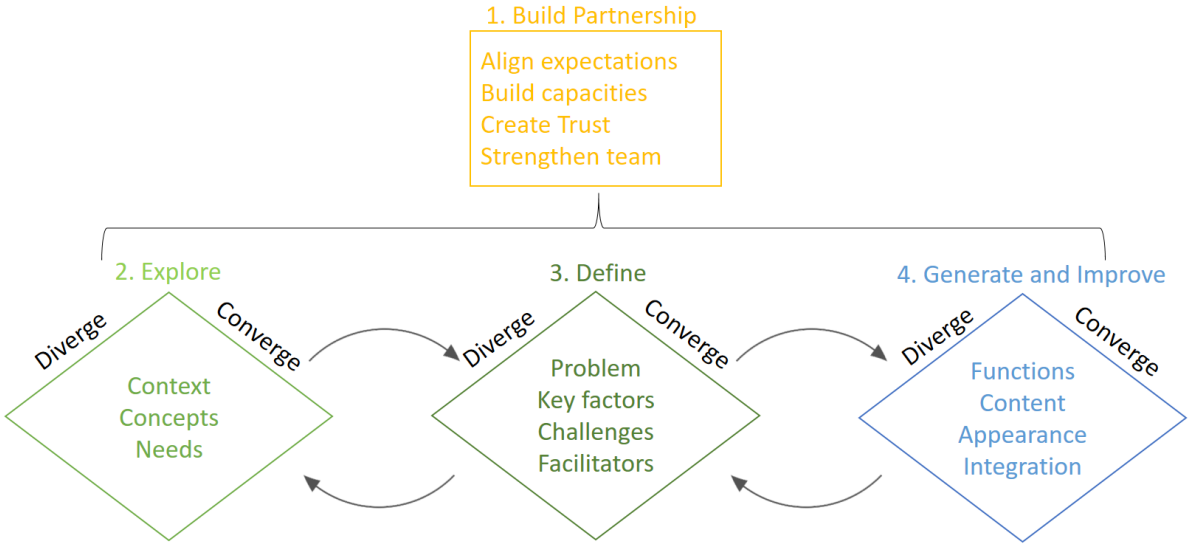


*Figure 1: SmartCHANGE Participatory Research Framework*

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*Table 3: Participatory ResearchFramework Explained*

| # | Phase | Phase Aims | Minimum no. research activities | | |
|---|---|---|---|---|---|
| | | | HCP | Families | Adolescents |
| **1** | Partnership | Prepare the participatory groups for a productive collaboration by creating a comfortable environment for learning and collaboration. | 2 | 2 | 1 |
| | | Gain insight into levels of knowledge, skills and trust regarding research, AI and risk prediction. | | | |
| **2** | Explore | Starting the collaboration in a way that enables creativity and critical thinking by allowing participants to explore and discuss their own experiences and perceptions | 2 | 3 | 7 |
| | | Explore participants context, conceptualizations and routines related to health behavior as well as motivation among families and adolescents to inform the later work related to defining the problem and designing the solution | | | |
| **3** | Define | Co-create an operational definition of the "problem" of health behavior among families and adolescents to increase ownership for the participants and gain an internal perspective on negative outcomes and underlying causes. | 1 | 2 | 5 |
| | | Brainstorm and ultimately prioritize the key factors associated with health behavior (i.e., challenges and facilitators) both to foster a greater understanding of the problem and to begin identifying actionable needs/challenges for the application. | | | |
| **4** | Generate and Improve | Generate ideas for content and functions that are desirable in an app, sort and prioritize these ideas in order to identify what is most important to participants. This includes generating ideas for explanations and visualizations within AI. | 4 | 5 | 10 |
| | | Reflect on the way in which a risk-prediction app could be integrated into existing routines and practices to help prepare for a successful implementation. | | | |
| | | Engage with participants to identify preferences, issues and gaps that could be addressed in ongoing iterations of the application. | | | |

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## 2.2 Outline of the research process

Using the structure emerging from the theoretical framework, the research process can be understood as having four phases for each group throughout the year (2024) as shown in the research timeline in Table 4. The number of sessions per phase and the activities that take place within them will be defined by a set of research goals created using the framework and input from consortium partners, as shown in Table 5. A total of 23 goals were identified, the order of which links to the research phase. The session number and research activity linked to the goal is shown for each stakeholder group. Further information can be found in the session guides below. Both the timeline and the table provide a preliminary structure that is subject to change based on the iterative nature of participatory research.

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*Table 4: Timeilne*

| | | 2024 | | | | | | | | | | | | 2025 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | | **January** | **February** | **March** | **April** | **May** | **June** | **July** | **August** | **September** | **October** | **November** | **December** | **Januari** |
| **HCPs** | Partnership building | Session 1 | | | | Session 5 | | | | | | | | |
| | Explore | | Session 2 | Session 3 | | | | | | | | | | |
| | Define | | | | Session 4 | | | | | | | | | |
| | Generate/ Improve | | | | | Session 6 | Session 7 | | | Session 8 | | | | Session 9 |
| **Families** | Partnership building | Session 1 | | | Session 7 | | | | | | | | | |
| | Explore | Sessions 2-4 | | | | | | | | | | | | |
| | Define | | | Sessions 5-6 | | | | | | | | | | |
| | Generate/ Improve | | | | Sessions 8-10 | | | | | Session 11 | | | | Session 12 |
| **Adolescents** | Partnership building | Session 1 | | | | | | | | | | | | |
| | Explore | Sessions 2-8 | | | | | | | | | | | | |
| | Define | | | Sessions 9-13 | | | | | | | | | | |
| | Generate/ Improve | | | | Sessions 14-21 | | | | | Session 22 | | | | Session 23 |
| | **Design** | Creating persona s or Mapping pain points | Defining gap & first brainstorm | Second brainstorm | First iteration clickable prototype | Revision clickable prototype | Submit Prototype for Deliverable | | | Formal feedback prototype | | | | Testing full prototype |

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### *Table 5: Goals and Activities*

| | | | HCP | | Families | | Adolescents | |
|---|---|---|---|---|---|---|---|---|
| **Phase** | **Goal No.** | **Goal description** | **Session no.** | **Suggested Activity** | **Session no.** | **Suggested Activity (children activity)** | **Session no.** | **Suggested Activity** |
| **Partnership** | **1** | Build a mutual learning environment (trust and empowerment) | 1 | Set team agreements | 1 | Set team agreements, Health Brainstorm (create a personal container) | 1 | Set team agreements (and ongoing) |
| **Partnership** | **2** | Explore and align expectations regarding the research process | 1 | Presentation and discussion of SmartChange project | 1 | Presentation and discussion of SmartChange project | 1 | Presentation and discussion of SmartChange project |
| **Partnership** | **3** | Identify ways of motivating ongoing participation | 1 | Discussion after project presentation | 1 | Discussion after project presentation | 1 | Discussion after project presentation |
| **Partnership** | **4** | Identify existing skills/knowledge levels relating to key concepts (i.e., research/AI/risk prediction 'sensitive data'' ) | 3, 5 | Presentation and discussion of SmartChange project, Presentation and discussion on AI | 3,7 | Presentation and discussion of SmartChange project | 2, 3, 4, 5 | Collage exercise, various workshops |
| **Partnership** | **5** | Build capacity to enable stakeholder participation | 5 | Presentation and discussion on AI | 7 | Presentation and discussion on AI | various | Various workshops |
| **Explore** | **6** | Understand the current actions, routines and daily context around the health behavior of families and adolescents. *Note- focused on actions rather than intentions* | 1 | Reflection on consultations exercise | 1, 2 | Health brainstorm exercise (Collage exercise), Timeline exercise (interview with an alien) | 2, 3, 4, 5 | Timeline exercise, conducting peer-research |
| **Explore** | **7** | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. | 1 | Brainstorm exercise (at-risk-child), Picture association exercise | 1, 3 | Health brainstorm exercise (Collage exercise) | 1,2 ,3 ,4, 5 | Graffiti wall activity |
| **Explore** | **8** | Explore how health-related decisions regarding children and adolescents are currently made and who has a say (+ to what extent) *Note: focused on intentions rather than actions* | 2, 3 | Reflection on consultations exercise, Brainstorm pain-points, Hypothetical case vignettes exercise, Factor diagram exercise | 2 | Circles of influence exercise (co-create cartoon) | 2 ,3, 4, 5 | Timeline exercise, neighborhood mapping exercise, conduct peer-research |

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| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Explore** | **9** | Identify support needs and what ideal circumstances to enable healthy behavior would look like according to participants | 2 | Brainstorm pain-points, Hypothetical case vignettes | 4 | Ideal Neighborhood activity | 6, 7, 8 | Ideal world exercise, conduct peer-research |
| **Explore** | **10** | Identify the underlying determinants that influence health decision making and health behavior | 2 | Brainstorm pain-points, Hypothetical case vignettes exercise, Jam Board exercise | 4 | Mind map activity (photovoice activity) | 6, 7, 8 | Ideal world exercise, conduct peer-research |
| **Explore** | **11** | Explore what motivates families and adolescents to change their behavior (and the specific role of future health risk as a motivator) | 2 | Reflection on consultations exercise, Jam board activity | 3 | Jam-board activity about previous support and brainstorm on digital sources (Brainstorm and sorting activity) | 6, 7, 8 | Motivation mind-mapping activity, conduct peer research |
| **Explore** | **12** | Identify perceptions of existing applications and tools to understand preferences (explanations, app interfaces, place in routine) | 3 | Gaps in support exercise | 3 | Jam-board activity about previous support and brainstorm on digital sources (Brainstorm and sorting activity) | 2, 3, 4, 5 | Workshops, Health App Research project |
| **Explore** | **13** | Explore stakeholder perceptions of risk prediction models and AI to establish a baseline for building trust and co-creating Explainable AI | 3,5 | Gaps in support exercise , presentation and discussion on AI | 3,7 | Jam-board activity about previous support and brainstorm on digital sources and presentation and discussion on AI | 6, 7, 8 | Presentation and discussion about AI and Health App research project |
| **Define** | **14** | Build a working definition of 'the problem' regarding health behavior among families and adolescents | 4 | Problem definition exercise | 5 | Creative problem framing exercise (Draw and write activity) | 9, 10, 11, 12, 13 | Analyze peer research, visualize data, create presentations and activity about problems statements. |
| **Define** | **15** | Understand which determinants of health behavior (both actionable and structural) are seen as significant by stakeholders (and which are most important) | 4 | Create simplified problem tree | 6 | Create simplified problem tree | 9, 10, 11, 12, 13 | Analyze peer research, visualize data, create presentations and activity about problems statements. |
| **Define** | **16** | Consolidate key gaps and challenges for which support is desired that fall within the scope of the app. | 6 | Bus-stop brainstorm activity, Serious Lego exercise | 6,8 | Bus-stop brainstorm activity, Serious Lego exercise (Cartoon together) | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **17** | Generating ideas for specific functions that address the gaps and needs generated previously | 6 | Serious Lego exercise, Thumbnail prototyping | 8 | Serious Lego Exercise, thumbnail prototyping (Crazy eights activity) | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |

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| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **Generate/ Improve** | **18** | Determine the type of explanations and visualizations desired by stakeholders | 5, 7, 8 | Presentation and discussion on AI, Feedback dicsussion | 7,8,10,11 | Deconstructing an app activity, Presentation and discussion on AI | 14, 15, 16 ,17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **19** | Prioritizing what ideas/aspects of ideas are the most important to stakeholders | 7 | Buy a Feature activity, Concept Poster creation | 9,10 | Buy a feature activity , concept poster creation (health invention activity) | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **20** | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these | 7,8 | Buy a Feature activity , Concept Poster creation | 9,10 | Concept poster creation (health invention activity) | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **21** | Establish how an app could be integrated into existing routines and what would be needed for it to be implemented smoothly | 8 | Brainstorm activity | 11 | Implementation brainstorm activity | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **22** | Generate feedback on the initial designs in order to identify the priorities and preferences of stakeholders (functions, visuals, explanations) | 8, 9 | Feedback discussion, Think-aloud activity, Rose thorn bud activity | 11, 12 | Feedback discussion, Think-aloud activity, Rose thorn bud activity | 14, 15, 16, 17, 18, 19, 21 | Various design-jam activities, workshops, design cycle project |
| **Generate/ Improve** | **23** | Spot gaps/issues or areas for potential improvement within full designs. | 9 | Think-aloud activity, rose thorn bud activity | 12 | Think-aloud activity, rose thorn bud activity | 22, 23, 24 | Think-aloud activity, rose thorn bud activity |

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# 3 General Session Outline

For participatory research sessions, a common structure exists as follows:

- Check-in: Ice-breakers (set the atmosphere, get to know each other, recap the previous session)
- Main body of research related activities interspersed with breaks/games, depending on context
- Check-out: summing up, reflecting, feedback, looking forwards to the next session.

The guides below show suggested activities for the main body of the session, though the final scripts and plans for sessions will be designed based on the emerging needs and priorities of the participants and facilitators. After each session, facilitators are expected to fill in a log book and reflection form including a small summary of the session to be provided to the research team including designers and the facilitators in other countries. Where applicable, data emerging directly from activities (i.e., collages, timelines etc.) will also be made available for discussion with facilitators and designers.

*Note: Structure, facilitation skills and specific activities will be covered in the training, along with specific capacity building related design, risk prediction models and explainability to enable facilitators to guide discussions effectively. These skills and considerations will continue to be addressed during facilitator meetings in which the scripts and plans for sessions are prepared.*

## 3.1 Structure of Session Outlines

Each section presents the minimum number of sessions and what will need to be covered within each session. Each guide provided below covers the same information in the same order. It begins with the session number and duration of the session, followed by a small table reiterating the goals covered within this session (as seen previously in Table 5). It further contains the following subheadings:

- Structure/organization notes
- Suggested activities (and homework where applicable)
- Expected Output (of specific activities)
- Use for design (where applicable)

Note that the activity descriptions are intentionally brief and will be further discussed in the training and included in the Appendix at a later date.

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# 4 Healthcare Practitioners

## 4.1 Partnership Phase: January, May 2024 (2 sessions)

### 4.1.1 Session 1 (90 minutes)

*Goals:*

| | |
|---|---|
| 1 | Build a mutual learning environment (trust and empowerment) |
| 2 | Explore and align expectations regarding the research process |
| 3 | Identify ways of motivating ongoing participation |
| 6 | Understand the current actions, routines and daily context around the health behavior of families and adolescents. |
| 7 | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. |

*Structure/organization notes*

Prior to the first session participants should have seen some form of project description. This session should take place in person, though future sessions may be organized online depending on the preferences of the participants.

*Suggested Activities:*

- Project Presentation
  - Expanding on the initial introduction of the project and allowing space for questions
- Brainstorm ‘the at risk child’
  - EITHER: sticky-note brainstorm on the characteristics of a child who is ‘at risk’ regarding health behavior
  - OR: within groups create a vignette/description of three children on different places on the spectrum from ‘at risk’ to ‘healthy’
- Practicalities discussion
  - Discuss time investment and strategies to make it easier to participate (e.g., online?)
- Team Agreements
  - Co-create a set of guidelines for how to interact within the space of these sessions to foster successful collaboration.
- Introducing the homework: Jam-board/worksheet
  - Explain the homework and expected duration (20-30 minutes)

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- Picture association activity: ideally on a jam board everyone can access, participants are asked to fill in sticky notes with their first thoughts/associations related to a series of images.
- Reflection on consultation activity: fill in/complete a template about their current experiences in consultations about child/adolescent health behavior.

*Expected Output:*

- List of questions asked after the initial presentation
- Products of the brainstorm activity (i.e., sticky notes)
- Facilitator interpretation of interpretation/definitions of 'risk' and 'health'
- Observations of group dynamics and anticipation of potential challenges/barriers to participation

*Use for Design*

Designers will use observations and notes from the facilitators to make definitions of healthcare practitioner personas.

### 4.1.2 Session 5 (90 minutes)

*Goals*

| | |
|---|---|
| 4 | Identify existing skills/knowledge levels relating to key concepts (i.e., research/AI/risk prediction 'sensitive data'') |
| 5 | Build capacity to enable stakeholder participation |
| 18 | Determine the type of explanations and visualizations desired by stakeholders |

*Structure/organization notes*

This session focuses on building the capacities healthcare practitioners need to engage in meaningful conversations about trust and explanations regarding the risk prediction model. Ideally all three of the goals listed can be covered in one session, though this will likely depend on how quickly sufficient understanding and dialogue can be reached. The subject of explanations should still come back in later sessions of the generate and improve phase.

*Suggested Activities*

- Knowledge clips

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- English language clip(s) created by relevant partners (with subtitles as needed) outlining key information on how AI models work and what kinds of outputs/explanations are possible
- Facilitators (who have been trained on the subject previously) answer any clarifying questions asked by participants

- Guided discussion
  - What kind of variables/data participants want to know about
  - What outputs and explanations participants want for specific cases
  - What interaction with the model participants want/need for trust

*Expected output*

- Detailed notes emerging from the discussions on questions asked and preferences voiced

## 4.2 Explore phase: February-March 2024 (2 sessions)

### 4.2.1 Session 2 (90 minutes)

*Goals:*

| | |
|---|---|
| 8 | Explore how health-related decisions regarding children and adolescents are currently made and who has a say |
| 9 | Identify support needs and what ideal circumstances to enable healthy behavior would look like according to participants |
| 10 | Identify the underlying determinants that influence health decision making and health behavior |
| 11 | Explore what motivates families and adolescents to change their behavior (and the specific role of future health risk as a motivator) |

*Structure/organization notes*

Bring back the team agreements at the start of the session, as well as some summary of the previous discussion on risk/health.

*Suggested Activities:*

- Brainstorm 'Pain Points' in consultation
  - Have participants put challenges from their homework reflection onto sticky notes and work on clustering them to identify the main 'pain points' or problem areas in consultations about health behavior (i.e., what is not going well currently)
- Hypothetical case vignettes/descriptions (note: careful consideration of how to construct these)

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    - Participants are given a set of vignettes of hypothetical cases (i.e., a patient profile) and asked to discuss in small groups how they think the consultation would go if they were to do it tomorrow- what challenges would they anticipate?
    - Have participants share what they discussed, and work in plenary to brainstorm what would need to be different in the circumstances of their consultations to avoid some of these challenges
- Introduce the homework: Jam board
    - Explain the homework and expected duration (20-30 minutes)
    - Based on the two activities, facilitators make a final set of categories of pain points. Participants are asked to rate which they find most challenging and list any existing tools they use (or could use) within these categories.
    - Write down some notes or thoughts in response to prompting questions aiming to get them thinking about the main factors that affect the health decision making of their patients.

*Expected Output:*

- Products of the brainstorm and the vignette discussion (picture of whiteboard/sticky notes)
- Observation of points of disagreement or differences between groups

*Use for Design*

Designers will revise and finalize the mapping of pain points based on the discussion.

### 4.2.2 Session 3 (90 minutes)

*Goals*

| | |
|---|---|
| 4 | Identify existing skills/knowledge levels relating to key concepts (i.e., research/AI/risk prediction 'sensitive data'') |
| 8 | Explore how health-related decisions regarding children and adolescents are currently made and who has a say (+ to what extent) |
| 12 | Identify perceptions of existing applications and tools to understand preferences (explanations, app interfaces, place in routine) |
| 13 | Explore stakeholder perceptions of risk prediction models and AI to establish a baseline for building trust and co-creating Explainable AI |

*Structure/organization notes*

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This session requires a smooth transition to move from challenges/routines to tools. This is a good point to organize an additional feedback moment. This is also a good moment to do a more extensive feedback/ check-in about how they are experiencing the participation.

### *Suggested Activities*

- Factor diagram exercise
    - In pairs, participants brainstorm factors using their first thoughts from the homework to make a diagram with a child at the center and different overlapping circles showing factors that impact health decision making (larger circle for more influence + the way factors intersect/overlap)
    - Participants share their diagrams in a plenary discussion and where possible facilitators will identify or introduce the topic of perceived health risks as a factor to explore how much an effect they feel this has.
- Gaps in support exercise
    - Leading a discussion based on the outcomes of the homework. Depends on if there are/ how many tools were identified and whether they are used.
    - The focus of the discussion in whichever case is to explore what makes a tool useful/ appealing/trustworthy and what makes it feel like extra work or a burden.
    - If there are no tools: why do they think this is the case. If there are tools but they are not used, why is this the case?
- Risk Prediction Practices
    - Using points emerging from the discussion above or the previous discussion on the at risk child, the facilitator leads a discussion about risk prediction in clinical practice
    - How do participants currently identify/predict risk? What factors do they take into account? What information do they use and what other information (if any) would they need?

### *Expected output*

- Diagrams of the factors identified
- Specific notes from the discussions or (if possible/necessary) anonymized transcripts of the discussions
- Thoughts from facilitators regarding the link to explanations/visualizations within the application

### *Use for Design (where applicable)*

Designers begin mapping gaps between needs and reality. They may also begin a first brainstorm about potential application functions that would fit these gaps.

## 4.3 Define Phase: April 2024, 1 Session

### 4.3.1 Session 4 (90 minutes)

*Goals*

| | |
|---|---|
| 14 | Build a working definition of 'the problem' regarding health behavior among families and adolescents |
| 15 | Understand which determinants of health behavior (both actionable and structural) are seen as significant by stakeholders (and which are most important) |

*Structure/organization notes*

During this session some time should be dedicated to planning session number 5 (see partnership phase).

*Suggested Activities*

- Problem definition
    - Facilitators create cards with challenges identified in previous sessions and provide one set to each small group of participants. The groups are asked to either select a particular challenge or summarize a set of challenges to define what they consider to be the most significant problem.
    - Groups then pitch their final problem statements and an attempt is made to reach consensus either by merging problem statements or through a system of voting. The final problem statement is then refined through phrasing and re-phrasing activities
- Simplified problem tree
    - Participants take their refined problem statement and place it at the top of a poster with a diagram of a tree. Sticky notes in different colors are then used to place symptoms of the problem in the branches, key aspect/sub-topics of the problem on the trunk and the causes at the roots.
- Introduce homework:
    - Explain the homework and expected duration (10-15 minutes)
    - Sticky notes from the roots of the tree diagram are filled in on a jam board. Participants then individually place the sticky notes on a matrix with the importance of the cause on the x axis and the difficulty of addressing it on the y axis. They then select/indicate the three causes they themselves would be most interested in addressing.

*Expected output*

- A list with the preliminary and final versions of the problems statements

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- Final pictures of the problem trees
- The various matrices with the priorities of participants indicated
- Specific notes on challenges reaching problem statements and how the final problem statements relate to the goals of the SmartCHANGE app.

*Use for Design*

Designers will compare the specific needs and priorities identified in the session with their gap spotting work and adjust accordingly. They will conduct a further brainstorm for application functions relating to this and may produce a first wire-frame mock-up of the application to share with facilitators for their feedback.

## 4.4 Generate and Improve Phase: May, June, September 2024 and January 2025 (4 sessions)

### 4.4.1 Session 6 (90 minutes)

*Goals*

| | |
|---|---|
| 16 | Consolidate key gaps and challenges for which support is desired that fall within the scope of the app. |
| 17 | Generating ideas for specific functions that address the gaps and needs generated previously |

*Structure/organization notes*

Set-up the room to invite creativity- e.g., small tables spaced around the room.

*Suggested Activities (both in session & 'homework' as indicated)*

- Bus-stop brainstorming
  - Four tables are set up around the room with different products from previous sessions placed on them (i.e., problem trees, hypothetical cases). In groups, participants take turns going to each table and discussing the material with a set of guiding questions
- Serious Lego
  - With a projection of the problem statement and their brainstorm as inspiration, participants are asked to create an object to represent their idea of the solution using Lego. This is not a concrete idea for a solution necessarily but for instance an impression of the characteristics it should have. Guiding questions and ongoing facilitation are provided to help them do so.
  - These are them shared with the group and explained

- Thumbnail prototyping
    - Can be approached in different ways- primarily focuses on rapid-fire ideas sketched out without too much reflection. This can be done with templates of a web-application format or free-form. A page of 6-8 such templates can also be passed in a circle so each person does one drawing and is inspired by other drawings on the page.

*Expected output*

- Pictures of the Serious Lego products with either captions or recordings of the explanations.

*Use for design*

Designers use the input from the participants as well as the feedback from the facilitators to create a draft of a clickable prototype as the first deliverable.

### 4.4.2 Session 7 (90 minutes)

*Goals*

| | |
|---|---|
| 18 | Determine the type of explanations and visualizations desired by stakeholders |
| 19 | Prioritizing what ideas/aspects of ideas are the most important to stakeholders |
| 20 | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these |

*Structure/organization notes*

Set-up the room to invite creativity- e.g., small tables spaced around the room.

*Suggested Activities*

- Buy a feature
    - Facilitators create a list of features based on the previous thumbnail prototypes and input from the designers. Monetary value is assigned based on the difficulty of implementing a given function (by designers or together with participants)
    - Small groups formed and given a budget to bid on/choose to purchase functions for their app to prioritize
- Concept poster
    - Using the chosen features groups then design an interface and an outline of functions for an application (where necessary using a template or guidance on how

an interface looks). Facilitators should also try to draw their attention back to the discussions from Session 5 (AI, explanations and data)
    - Participants present the posters to each other and give tops and tips to other groups (what is good, what could be improved) as sticky notes

*Expected output*

- An overview of the prices and bidding choices of each groups
- The final concept posters with sticky-notes of feedback
- The exact prices and bidding choices of each group as well as their final concept poster and sticky notes for feedback.
- Facilitators notes specifically on the attribution of value, and for instance if there was clear consensus or very different approaches, as well as their choices regarding explanations and visualizations

*Use for design*

Designers will revise their clickable prototype and prepare it to be shared with participants in the next session

### 4.4.3 Session 8 (60 minutes)

*Goals*

| | |
|---|---|
| 18 | Determine the type of explanations and visualizations desired by stakeholders |
| 20 | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these |
| 21 | Establish how an app could be integrated into existing routines and what would be needed for it to be implemented smoothly |
| 22 | Generate feedback on the initial designs in order to identify the priorities and preferences of stakeholders (functions, visuals, explanations) |

*Structure/organization notes*

It is important to consider how the presenting of the prototypes will be done as well as how notes of the discussions will be prepared.

*Suggested Activities*

- Presentation of clickable prototype

    - Facilitators briefly present the clickable prototype using notes from the designers.
    - Participants are given copies of the prototype to look at and are split into small groups to note their first tips and tops regarding the functions.
- AI and risk prediction model feedback
    - Assuming some ideas about the risk prediction model (e.g., what data is covered) and the AI explanations/visualizations are ready to be shared, a similar presentation and discussion of these can take place.
    - Alternatively, a list of specific questions from partners working on these aspects can be brought to discuss with participants
- Implementation brainstorm
    - Facilitators prepare a set of guiding questions to reflect with participants on how the prototype would fit within a clinical routine. Specific attention should be paid to how it would work within current routines, whether it would reduce or add work and whether they would recommend it to their colleagues (why/why not)

*Expected output*

- Lists of plus and minus points and notes from the other discussions

*Use for design*

During the summer, designers will work (as far as possible) to develop a working prototype for participants to engage with during the next session.

### 4.4.4 Session 9 (45 minutes)

*Goals*

| | |
|---|---|
| 22 | Generate feedback on the initial designs in order to identify the priorities and preferences of stakeholders (functions, visuals, explanations) |
| 23 | Spot gaps/issues or areas for potential improvement within full designs. |

*Structure/organization notes*

If it has been a longer time since the previous session, ice-breakers should be somewhat longer to get the energy and enthusiasm going again.

*Suggested Activities*

- 'Think-aloud'
    - Participants test out the app while speaking out loud with a voice recording device, to share their thoughts in real time

- Rose thorn bud
    - Brainstorm with sticky notes for rose (what is good) thorn (what was an issue) and bud (what things have further potential that could be developed)

### *Expected output*

- Anonymized transcripts of the think alouds
- Sticky notes from the rose-thorn-bud discussion

### *Use for design*

Designers will be able to refine their design based on this feedback

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# 5 Families

## 5.1 Partnership phase: January, May 2024 (2 sessions)

### 5.1.1 Session 1 (90 minutes)

*Goals:*

| | |
|---|---|
| 1 | Build a mutual learning environment |
| 2 | Explore and align expectations regarding the research process |
| 3 | Identify ways of motivating ongoing participation |
| 6 | Understand the current actions, routines and daily context around the health behavior of families and adolescents |
| 7 | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. |

*Structure/organization notes*

Prior to the first session participants should have seen some form of project description. Questions about what would incentivize participation and whether children should be involved should have been investigated prior to recruitment and could also be asked again in an initial registering email exchange of some kind. However, it is important to explore further with the group- do they want to work on their family health as well as sharing their experiences? Do they want workshops related to this? How should children be involved? Together with parents or separately? Note that the structure of any session with children would be slightly different, involving ice-breaker games and a movement activity each time.

*Suggested Activities:*

Parents

- Project Presentation
    - Facilitators present briefly, expanding on the information provided previously and allowing space for questions and clarification.
- Health brainstorm (ideals and reality)
    - Facilitators choose a format for a brainstorm about health (what it means, what is healthy behavior)- this could be a mind map, a collage or a graffiti wall.

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    - Each participant then makes an anonymous note (via Mentimeter or Jamboard for instance) about how their reality differs from this ideal of health.
    - Each person then takes a note other than their own and explains it to the group- the facilitator guides this process to achieve the aim of taking the shame and pressure out of the conversation about health (nobody is perfect and everyone has empathy for how difficult it can be as parents to achieve the ideal of health)
- Practicalities discussion
    - Discuss the participation of children
    - Discuss time investment and strategies to make it easier to participate (e.g., online?)
- Team Agreements
    - Co-create a set of guidelines for how to interact within the space of these sessions to foster successful collaboration.

Children

- Project presentation
    - Explain in simple language what they will be doing here and why
- Personal container
    - Help children decorate the inside and outside of a box to show both what is easily visible to know about them (outside) and what people may not see right away on the inside
    - Allow them to share only what they want to with the group
- Collage
    - With relevant materials, ask children to make a collage on what 'healthy' means to them

*Expected Output:*

- An output of the brainstorm with parents (collage, mind-map, etc.) and the collages made with children
- Sticky notes about the differences between their ideals and reality regarding health behavior
- Facilitators observations of group dynamics and anticipation of potential barriers/challenges in participation

*Use for Design*

Designers will use the brainstorms and sticky notes to begin mapping the needs and challenges experienced by parents.

### 5.1.2 Session 7 (90 minutes)

*Goals*

| | |
|---|---|
| 4 | Identify existing skills/knowledge levels relating to key concepts (i.e., research/AI/risk prediction 'sensitive data'') |

| | |
|---|---|
| 5 | Build capacity to enable stakeholder participation |
| 18 | Determine the type of explanations and visualizations desired by stakeholders |

*Structure/organization notes*

This session focuses on building the capacities parents need to engage in meaningful conversations about trust and explanations regarding the risk prediction model. Ideally all three of the goals listed can be covered in one session, though this will likely depend on how quickly sufficient understanding and dialogue can be reached. The subject of 'explanations' should still come back in later sessions of the generate and improve phase.

*Suggested Activities*

- Knowledge clips
  - Facilitators show English language clip(s) created by relevant partners (with subtitles as needed) outlining key information on how AI models work and what kinds of outputs/explanations are possible
  - Facilitators (who have been trained on the subject previously) answer any clarifying questions asked by participants
- Guided discussion
  - What kind of variables/data participants want to know about
  - What sorts of explanations participants would want regarding risk
  - What interaction with the model should be possible to create trust/understanding

*Expected output*

- Detailed notes emerging from the discussions on questions asked and preferences voiced

## 5.2 Exploration Phase: January, February 2024 (3 sessions)

### 5.2.1 Session 2 (90 minutes)

*Goals:*

| | |
|---|---|
| 6 | Understand the current actions, routines and daily context around the health behavior of families and adolescents |
| 8 | Explore how health-related decisions regarding children and adolescents are currently made and who has a say (+ to what extent |

*Structure/organization notes*

Bring back the team agreements at the start of the session, as well as some summary of the previous discussion. Reflect on their definition of health and check if information during the research would be desirable (i.e., are there misunderstandings about health that need to be addressed, are there certain topics where they lack information?).

*Suggested Activities:*

Parents

- Timeline Exercise
    - Participants are split into small groups and asked to make a timeline for a hypothetical 'average' classmate of their child, marking health factors like when they sleep, when there is movement in their day, when and what they eat.
    - Groups then share their timelines with each other. Participants then return to their small groups and brainstorm on one change that could be applied that would improve the health of each of the timelines shared.
- Introduction of the homework (Circles of influence) and anticipated time it costs (20 minutes)
    - Participants are tasked with creating a diagram as follows: a child in the center of the page with overlapping circles around them that show all the actors that have an influence on their health behavior. The size of the circle shows the amount of influence, and there can be overlap between actors that are interlinked.

Children

- Interview with an alien
    - The facilitator introduces a puppet to the group who is an alien who is curious about what a human child's life is like. Children take turns talking to the alien and trying to explain a bit about their life.
    - Children should be prompted to explain with extra clarity and detail because the alien doesn't have any context to understand their lives. The alien puppet can also ask clarifying questions about things.
- Co-create cartoon
    - On a template for a cartoon, with support from facilitators/parents, children draw an explanation about why they do something they consider healthy (e.g., why they play sports, why they eat healthy snacks)

*Expected Output:*

- Timeline drawings made by parents
- Circles of influence drawings
- Cartoons made by children
- Specific notes on the changes parents consider making

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- Specific notes on the explanations children gave to the alien

*Use for Design*

Designers continue mapping the needs of parents focusing on the pain points or challenges they experience, and begin an initial identification of gaps between their needs and experiences where a solution could be beneficial.

### 5.2.2 Session 3: (90 minutes)

*Goals:*

| | |
|---|---|
| 4 | Identify existing skills/knowledge levels relating to key concepts (i.e., research/AI/risk prediction 'sensitive data'' ) |
| 7 | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. |
| 11 | Explore what motivates families and adolescents to change their behavior (and the specific role of future health risk as a motivator) |
| 12 | Identify perceptions of existing applications and tools to understand preferences (explanations, app interfaces, place in routine) |
| 13 | Explore stakeholder perceptions of risk prediction models and AI to establish a baseline for building trust and co-creating Explainable AI |

*Structure/organization notes*

This would be a good moment to plan a more detailed feedback discussion on how the sessions are going and how the experience of participants could be improved.

*Suggested Activities:*

Parents

- Jam boards and discussions (current experiences/support)
    - Facilitators lead a discussion based on the homework asking participants about actors that influence children's health behavior and specifically identifying those who provide support or information to parents.
    - Facilitators then ask them to add to this new list with any other sources of information on health or support for health behavior

- If it does not come up by itself, facilitators will then ask if there are any digital sources of information (e.g., apps, Instagram etc)
- Using prompting questions, facilitators will then explore with parents key topics such as sensitive data, trust in sources of information and the relationship between perceived health risks and motivation for health behavior.

Children

- Brainstorm + sorting activity
  - Facilitators help children come up with a brainstorm for instance as a word cloud on a white-board of different activities they do outside of school. This will likely begin with specific activities like clubs or sports, then the facilitator should guide them towards what they do by themselves at home as well (e.g., types of play, the use of any apps or games on phones/tablets)
  - Facilitators will then help children create categories for the activities and group them together.
  - For each category, children then play a game aiming at listing what is fun about each one- why do they do it?
    - E.g., most items listed in 5 minutes gets to decide what they do for the movement activity that day

*Expected Output:*

- The lists of sources of information and support created with parents
- A list of the different apps/games children use and the various lists about what motivates them to do certain activities
- Specific notes from facilitators on the topic of sensitive data, trust and the types of explanations parents respond to.

*Use for Design*

Designers will be able to add the current sources of information and support to their mapping to enable more precise gap spotting. This session will also provide them with initial ideas on the functions parents like and their preferences regarding data sharing/trust

### 5.2.3 Session 4 (90 minutes)

*Goals:*

| | |
|---|---|
| 9 | Identify support needs and what ideal circumstances to enable healthy behavior would look like according to participants |
| 10 | Identify the underlying determinants that influence health decision making and health behavior |

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### *Structure/organization notes*

This session would lend itself well to a collaboration with parents and children – in which case the activities for children would be done together with parents.

### *Suggested Activities*

Parents

- Discussion and Mind Map
    - Facilitators bring back some of the products from previous sessions as examples and ask participants in small groups to come up with a list of factors that affect their health decisions.
    - The lists created by each group are brought together on sticky notes and then participants are asked to cluster them together to form overall categories.
- Ideal neighborhood map
    - Using this overview of factors, participants are then asked in their small groups to draw up a map of the ideal neighborhood for raising active, healthy kids.

Children

- Kinetic drawing
    - Children (together with their parents) create two drawings- one of a time during the day that they sit still (this is a normal drawing) and one of a time when they are moving (this is a kinetic drawing- the drawing should show movement). Captions can be made to explain the images
    - These drawings are then shared with the group
- Ideal neighborhood map
    - With the previous activity as inspiration, participants are then asked to make a map of a neighborhood where it is fun and easy to move every day.
    - These too will be explained to the group
- Introduce homework activity (photovoice) and duration (10 minutes a day for two weeks)
    - Photovoice is a data collection method where people take pictures of things in their lives related to a particular topic or theme and explain them with a caption- it allows them to give voice to their own experiences and experiential knowledge
    - Children are either given a camera to use, or asked to work with their parents and use their parents' camera/phone (together).
    - Facilitators will decide on a theme based on the session thus far to focus e.g., on movement during the day or on what they eat.

### *Expected Output:*

- Lists of factors and categories/ kinetic drawings with captions
- Neighborhood maps
- Photos with captions

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- Facilitators thoughts on the type of issues identified- are they more structural or actionable within the scope of the app?

*Use for Design*

Designers will finalize their gap spotting and mapping of pain points and use these as the basis for the first brainstorm of potential solutions.

## 5.3 Define Phase March 2024 (2 sessions)

### 5.3.1 Session 5 (90 minutes)

| | |
|---|---|
| 14 | Build a working definition of 'the problem' regarding health behavior among families and adolescents |

*Structure/organization notes*

This would be a good point to have another detailed feedback moment. The type of creative activity included in this session should link to the specific skills and comfort level of the facilitator.

*Suggested Activities*

Parents

- Creative problem framing
    - Use e.g., collage, role-play, short stories or other creative medium to have participants frame their current understanding of what is 'the problem' regarding health behavior
    - Regardless of the format, facilitators could use the idea of a spectrum from a struggling child to a thriving child (regarding health behavior) to structure the exercise e.g., collages at different points in this spectrum, short stories about alternate universes or having them role play interactions with children at different points on this spectrum.
- Drafting problem statements
    - In small groups, participants draft a problem statement based on the creative exercise.
    - These are shared within the plenary group, after which they try out phrasing and re-phrasing the statement to refine it.

Children

- Draw and write
    -

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- Participants are supported in creating a drawing with a caption that answer a problem-framing question chosen by the facilitator (e.g., why is it difficult to be healthy sometimes?)

*Expected Output:*

- Creative products (collage, script, story etc.) and drawings.
- List of problem statements and various versions thereof
- Specific notes from facilitators about the potential for reaching consensus on an overall problem statement.

*Use for Design*

The various problem statements are checked with the designers own definitions of the key challenges/needs of participants. This is used as input for the second brainstorm on solutions.

### 5.3.2 Session 6 (90 minutes)

| | |
|---|---|
| 15 | Understand which determinants of health behavior (both actionable and structural) are seen as significant by stakeholders (and which are most important) |
| 16 | Consolidate key gaps and challenges for which support is desired that fall within the scope of the app. |

*Structure/organization notes*

Depending on the age of the children, facilitators could also decide to focus on parents for this session and have a more open-ended creative session with children.

*Suggested Activities*

Parents

- Problem statement sorting
  - Using stickers or a bus-stop system, participants attempt to reach consensus on a problem statement or a subset of problem statements from the previous session
- Simplified problem tree
  - Participants take their refined problem statement and place it at the top of a poster with diagram of a tree. Sticky notes in different colors are then used to place symptoms of the problem in the branches, key aspects sub-topics of the problem on the trunk and the causes at the roots.
  - Participants then place causes on a matrix with the importance of the cause on the x axis and the difficulty of addressing it on they y axis

Children

- Simplified problem tree
    - Participants are given a large diagram of a tree that they can decorate as they see fit
    - They are then asked to take some of the problems emerging from the previous session and add them on the top of the tree
    - The facilitator then helps them in thinking about the reason why the problems exist by asking “why” and having them draw or write the explanation further down the tree, to try to get to the roots.

*Expected output*

- Pictures of problem trees with the issues and their causes
- The final matrix that helps to show how parents prioritize issues
- Specific notes from facilitators on how the problem statements and identified causes relate to the research project (i.e., risk prediction, applications)

*Use for Design*

Designers can use these overviews of the problems in the selection of which functions from the brainstorms would align with the priorities of families. This will inform the creation of the first wire-frame of the application that will be shared with the facilitators for feedback.

## 5.4 Generate and improve Phase: May-June (5 sessions)

### 5.4.1 Session 8 (90 minutes)

*Goals*

| | |
|---|---|
| 16 | Consolidate key gaps and challenges for which support is desired that fall within the scope of the app. |
| 17 | Generating ideas for specific functions that address the gaps and needs generated previously |

*Structure/organization notes*

If children are participating this session would work best if parents and children are together in one session. In this case, the combined groups would follow the activities described in the ‘children’ section below.

*Suggested Activities*

Parents

- Bus-stop brainstorming
    - Four tables are set up around the room with different products from previous sessions placed on them. In groups, participants take turns going to each table and discussing the material they find there with a set of guiding questions.
- Serious Lego
    - With a projection of the problem statement and their brainstorm as inspiration, participants are asked to create an object to represent their idea of the solution using Lego. This is not a concrete idea for a solution necessarily but for instance an impression of the characteristics it should have. Guiding questions and ongoing facilitation are provided to help them do so.
    - These are them shared with the group and explained
- Thumbnail prototyping
    - Can be approached in different ways- primarily focuses on rapid-fire ideas sketched out without too much reflection. This can be done with templates of a web-application format or free-form. A page of 6-8 such templates can also be passed in a circle so each person does one drawing and is inspired by other drawings on the page.

Children

- Cartoon together
    - Materials from the define phase are placed on display around the room and children are given the chance to showcase some of their work if the parents have not seen it.
    - With this inspiration, participants work together to make a cartoon about the problem could be solved- this does not have to be realistic, but should be creative and fun.
- Serious Lego
    - Facilitators give some examples of how mascots are representations of certain products or organizations. Participants are then asked to use Lego to create a mascot for the solution to the problem. The mascots are then shared an discussed within the group
- Crazy eights
    - Similar to thumbnail prototyping, but with eight specific boxes of templates
    - Potential addition of movement/excitement going from one table to the next within a certain timeframe for drawing

### *Expected output*

- Cartoon drawings
- Pictures of serious Lego products with captions
- Thumbnail prototype drawings

### *Use for design*

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Designers will use both the facilitator feedback and the initial ideas generated in this session to revise the clickable prototype (which will then be submitted as a deliverable).

### 5.4.2 Session 9 (90 minutes)

*Goals*

| | |
|---|---|
| 18 | Determine the type of explanations and visualizations desired by stakeholders |
| 19 | Prioritizing what ideas/aspects of ideas are the most important to stakeholders |
| 20 | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these |

*Structure/organization notes*

This session could be run with parents only, or simplified to run with children (i.e., setting up buy a feature more like a card game with clear rules). Set-up the room to invite creativity- e.g., small tables spaced around the room.

*Suggested Activities (both in session & 'homework' as indicated)*

- Deconstruct an app
  - Facilitators send an email prior to the session asking parents to send a list of applications related to health behavior (in any way) that they like.
  - Participants are divided into groups and given an application to analyze. They are asked to 'deconstruct' it into a list of functions or aspects that it has.
  - They are asked to reflect on what they like or dislike about each function. In particular they should be asked to think about what types of explanations the app uses (link to session 7)
- Buy a feature
  - Facilitators prepare a list of features/functions of applications based on the prototypes form the previous session and some input from designers (with some blank cards to add any new functions emerging from the deconstructing an app exercise)
  - The cards have pre-assigned monetary values (designers + facilitators decide) based on e.g., how difficult they are to implement.
  - Participants are broken into groups again and given a budget with which to bid on specific functions.

*Expected output*

- The deconstructed list of functions and their thoughts on them
- An overview of the bidding choices made by each group
- Notes from facilitators on the decision making process regarding bidding choices

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*Use for design*

These outputs can be used by designers for a further revision of the prototype

**Session 10**

*Goals*

| | |
|---|---|
| 18 | Determine the type of explanations and visualizations desired by stakeholders |
| 19 | Prioritizing what ideas/aspects of ideas are the most important to stakeholders |
| 20 | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these |

*Structure/organization notes*

Set-up the room to invite creativity- e.g., small tables spaced around the room.

*Suggested Activities*

Parents

- Concept poster
    - Participants are given the ideas, Lego and cards from the last two sessions as inspiration and put into groups to create a concept poster for an application
    - Some templates of applications are provided to help them structure it, as well as a number of creative materials
    - They present these to each-other and give tops and tips to other groups (what is good, what could be improved) as sticky-notes

Children

- Health invention
    - Similar to the concept poster, but more open ended allowing their invention idea to go beyond the limitations of an app

*Expected output*

- The concept posters and the feedback from participants
- Specific notes on consensus or differences of opinion and the use of explanations/risk prediction within the applications

*Use for design*

Designers will make a further revision and continued development of the prototype which will be prepared to be shared with participants.

### 5.4.3 Session 11

| | |
|---|---|
| 18 | Determine the type of explanations desired for AI and generate specific ideas for visualizations or interactions to that end |
| 21 | Establish how an app could be integrated into existing routines and what would be needed for it to be implemented smoothly |
| 22 | Generate feedback on the initial designs in order to identify the priorities and preferences of stakeholders |

*Structure/organization notes*

This session would take place with parents only. It is important to consider how the presenting of the prototypes will be done, as well as how the feedback can best be shared with designers (should notes be taken? Transcripts of recordings?).

*Suggested Activities*

- Presentation of clickable prototype
  - Facilitators show a brief video where the designers introduce the clickable prototype.
  - In small groups, they are given the chance to click through it and make a list of 'tops' (what they like) and 'tips' (what could be improved), focusing on the functions rather than the appearance
  - Discussion in small groups and initial plus and minus points
- Discussion on risk prediction and AI
  - Where possible, some work on explanations and visualizations would be presented here, or alternatively a list of specific questions prepared by consortium members working on this would be brought to participants to discuss.
- Implementation brainstorm
  - Facilitators prepare a list of prompting questions to discuss the place the application would have in their daily routines and how use could be strengthened.

*Expected output*

- Lists of plus and minus points and notes from the other discussions

*Use for design*

Designers should be able to use this input to continue on to the creation of a functional prototype

### 5.4.4 Session 12 (60 minutes)

*Goals*

| | |
|---|---|
| 22 | Generate feedback on the initial designs in order to identify the priorities and preferences of stakeholders |
| 23 | Spot gaps/issues or areas for potential improvement within full designs. |

*Structure/organization notes*

Parents and children should do this together assuming the app will be used together, regardless of if children have participated thus far. If it has been a longer time since the previous session, ice-breakers should be somewhat longer to get the energy and enthusiasm going again.

*Suggested Activities (both in session & 'homework' as indicated)*

- 'Think-aloud-s'
  - Participants test out the app while speaking out loud with a voice recording device, to share their thoughts in real time
- Rose thorn bud
  - Brainstorm with sticky notes for rose (what is good) thorn (what was an issue) and bud (what things have further potential that could be developed)

*Expected output*

- Recordings of the think-aloud-s and sticky notes from the discussion

*Use for design*

This will be the final input designers can use to refine the app.

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# 6 Adolescents

## 6.1 Partnership Phase: January 2024 (1 session)

### 6.1.1 Session 1

*Goals:*

| | |
|---|---|
| 1 | Build a mutual learning environment (trust and empowerment) |
| 2 | Explore and align expectations regarding the research process |
| 3 | Identify ways of motivating ongoing participation |
| 7 | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. |

*Structure/organization notes*

Prior to the first session participants should have been introduced briefly to the project for instance through a brief presentation in their classes as part of recruitment. Information should also have been provided to their parents for instance in the form of pamphlets, and full informed consent should have been obtained.

*Suggested Activities:*

- Project Presentation
  - Expanding on the initial introduction of the project and allowing space for questions, clarifying the space and role of the participants as co-researchers and co-designers.
- Graffiti wall
  - Participants are split into groups and asked to brainstorm what health means to them and to draw/write out some of their ideas on paper.
  - The facilitator then introduces the graffiti wall (a large canvas or actual wall) and materials such as spray cans and acrylic markers for them to fill in some of the ideas from their brainstorm.
- Practicalities discussion
  - Discuss time investment (in sessions and outside of sessions)
- Team Agreements
  - Co-create a set of guidelines for how to interact within the space of these sessions to foster successful collaboration.

*Expected Output:*

- Pictures of the graffiti wall, as well as future adjustments that will be made to it

- Lists of any questions asked after the presentations
- Observations from facilitators of group dynamics and anticipation of potential barriers/challenges in participation

## 6.2 Explore Phase: January- (May 7 sessions)

### 6.2.1 Sessions 2-5 (60 minutes)

*Goals*

| | |
|---|---|
| 3 | Build capacity to place stakeholders on equal footing as co-researchers |
| 6 | Understand the current actions, routines and daily context around the health behavior of families and adolescents. |
| 7 | Understand how participants themselves interpret key terms such as 'health', 'risk' etc. |
| 8 | Explore how health-related decisions regarding children and adolescents are currently made and who has a say (+ to what extent) |
| 12 | Identify perceptions of existing applications and tools to understand preferences (explanations, app interfaces, place in routine) |

*Structure/organization notes*

In the first session of this series it is important to bring back the graffiti wall and team agreements from the previous session. Each session will follow the following structure: ice-breaker, revisit previous session and homework, and the main body consisting of a creative component, workshop or peer-research session. In these initial sessions, focusing on getting good group collaborations going and doing some team-building is essential.

*Suggested Activities:*

Creative components

- Timeline- average day
    - Facilitators collaborate with participants to create a character of a hypothetical classmate (what's their name? where do they live?) In group, participants then make

a timeline of their average day. Each group reflects on whether things written on the graffiti wall come up or not (and why).

- Neighborhood mapping
  - Linked to their research project and their chosen research question.
  - Participants make a make of their neighborhoods and note down spaces associated with their chosen topic
- Collage health risk
  - Participants create a collage on what health risk is/ what is unhealthy behavior
  - As each person shares their collage and explains it, the facilitator guides discussions about motivation and health behavior (why do people do things that are unhealthy?)

### Research Activities

- Other apps research project
  - Participants conduct an initial literature focused research as a practice for research skills they will apply for the peer-research (i.e., deciding on a research question)
  - Participants will decide on a research focus that addresses current apps focused on health behavior. They will investigate by looking at apps online themselves and reading articles/reviews. They will practice presentation skills when they present their findings.
  - *Note: specific attention should be paid to explanations and visualizations- what they like and dislike. This can later be linked in during workshops on design and AI*
- Peer research (observation)
  - In groups, participants will begin their peer research by practicing observation related to their research question. This involves observing their peers, but also themselves through e.g., journaling or photo-voice

### Workshops

- Health and behavior (optional)
  - Depending on knowledge shown in initial sessions, cover elements like sleep, diet, hydration, movement and sedentary behavior and health consequences.
- Introduction to research
  - Types of research, types of questions etc.
- Deciding on a research question
  - Presentation and practice by making a research question for a minor homework project about health apps.
- Searching literature and critical reading (optional)
  - Where do you find useful information about a research topic? How do you assess the quality of a source and how do you read critically and quickly? (for first project)
- Presentation skills
  - Before first presentation on minor project
- Observation research (ethnography and auto-ethnography)
  - On keeping a field journal of observations about their peers

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- Photo-voice, journaling or vlogging as data collection

*Expected output*

- Timelines, maps and collages from creative components
- Presentations about other apps (slides + recorded)
- Research project- observations and journal entries

*Use for design*

Designers will conduct context analysis on the basis of the data, and/or journey maps of the day with pain points/challenges identified.

### 6.2.2 Session 6-8

*Goals*

| | |
|---|---|
| 5 | Build capacity to place stakeholders on equal footing as co-researchers |
| 10 | Identify the underlying determinants that influence health decision making and health behavior sub-sets of contextual factors that influence health decision making and the degree to which they do so |
| 11 | Explore what motivates families and adolescents to change their behavior (and the specific role of future health risk as a motivator) |
| 12 | Identify perceptions of existing applications and tools to understand preferences (explanations, app interfaces, place in routine) |
| 13 | Explore stakeholder perceptions of risk prediction models and AI to establish a baseline for building trust and co-creating Explainable AI |

*Structure/organization notes*

In a similar structure to the previous sessions, this set of sessions marks the next phase of research focused on peer research. It will be important to plan in reflection on the group-work so far to make sure they are collaborating well. The first session of this set should also include a feedback moment for the participation so far.

*Suggested Activities:*

Creative components

- Ideal world

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    - Exploring needs through activities that imagine a more ideal world for health behavior. Depends on facilitator: short stories, draw and write, role-play.
- Motivation mind-mapping
    - Working with the data from the previous sessions on observation, participants will make a mind-map focused on understanding their peers motivations regarding health behavior.

Research Activities

- Chosen data-collection method
    - During sessions and as homework, the groups will collect further data on peers health behavior and choose a data-collection method to do so. Workshops will be specific to their needs.

Workshops

- Ethics in research
    - Getting informed consent
- Designing an interview
    - A structured or less structured approach, deciding what topics to cover, finding people to participate.
- Carrying out an interview
    - Theory and practice for effective interviewing (practicing on each other)
- Designing a questionnaire
    - Types of interview questions, what order they should be in etc. Piloting each other's questionnaires

*Expected output*

- Mind maps and ideal world products
- The research questions and e.g., interview guides/ questionnaire questions designed by participants
- Data collected by the participants as soon as available

*Use for design*

Designers will work on mapping gaps between ideals and reality based on the incoming data and begin the first few iterations of brainstorms about solutions

## 6.3 Define Phase: March-April 2024 (5 sessions)

### 6.3.1 Sessions 9-13

*Goals*

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| | |
|---|---|
| 5 | Build capacity to place stakeholders on equal footing as co-researchers |
| 14 | Build a working definition of 'the problem' regarding health behavior among families and adolescents |
| 15 | Understand which determinants of health behavior (both actionable and structural) are seen as significant by stakeholders (and which are most important) |

*Structure/organization notes*

These sessions overlap somewhat with the explore phase, but aim to use the findings of the exploratory research to begin defining the problem. Sessions focused on visualizing and analyzing data can transition towards forming problem statements that are used for design.

*Suggested Activities:*

Creative component:

- Visualizing data
    - How to represent and further analyze your findings in e.g., diagrams, charts, problem trees, word clouds

Workshops:

- Data analysis
    - Coding and basic descriptive statistics
- Presentation skills recap (+ presenting data)
- Behavior and Motivation (optional)
    - In preparation for the design activities, their own findings could be supplemented/interpreted by understanding some of the basics of behavior and motivation theories (depending on age/knowledge etc.)

Research:

- Presenting previous findings
    - A presentation evening using either slides or posters where they can answer their research questions
- Problem statement
    - Following the presentation of their findings, each group comes up with a problem statement related to health and behavior among their peers they would be interested to address with an app design.
    - These can be shared in plenary or even developed plenary by consensus and new groups could be formed for design activities.

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*Expected output*

- Various visualizations of their data and interpretations thereof
- Presentations/posters on an aspect of health and behavior participants find important
- General reflection forms from each session

*Use for design*

Designers will be able to refine/finalize their gap spotting and brainstorming in order to create the first designs of the clickable prototype. The first version will be shared with facilitators for their feedback.

Comparing problem statements to determined gaps and initial ideas. Revision of brainstorm ideas and first designs/prototyping to share with facilitators

## 6.4 Generate and Improve April-June (10 sessions)

### 6.4.1 Session 14-21

*Goals*

| | |
|---|---|
| 5 | Build capacity to place stakeholders on equal footing as co-researchers |
| 16 | Consolidate key gaps and challenges for which support is desired that fall within the scope of the app. |
| 17 | Generating ideas for specific functions that address the gaps and needs generated previously |
| 18 | Determine the type of explanations and visualizations desired by stakeholders |
| 19 | Prioritizing what ideas/aspects of ideas are the most important to stakeholders |
| 20 | Determine which visual elements/stylistic choices matter to stakeholders and what sorts of preferences they have regarding these |
| 21 | Establish how an app could be integrated into existing routines and what would be needed for it to be implemented smoothly |

*Structure/organization notes*

Over the remaining weeks, participants begin the project working towards their own clickable prototype for an app based on the established problem statements and in response to their research. The first few sessions will focus on design-jam elements to get creative ideas started, after which it will increasingly be a cycle of design workshop, design practice and feedback session. Feedback sessions will also include direct feedback on the prototypes of the design team (reciprocal)

*Suggested Activities:*

Creative components:

- Serious Lego
  - Creation of a mascot for the solution to the problem
- Crazy eights
  - High speed solution generation in 8 boxes with templates
- Hand heart mind
  - Thinking about how a solution should be effective (mind), practical (hand) and emotionally engaging (heart)
- Round robin board
  - A board with ideas about solutions that can be shared between different study sites
- Newspaper article
  - An article supposing the design they have made is already out there and successful. What would be said about it? (helps identify their priorities)
- Rose-Thorn-Bud
  - Feedback practice focusing on what is appealing, what is challenging and what has potential.

Workshops:

- Principles of design
  - Simplified information on some of the theory behind design
- Risk modeling and design
  - What are models (and transparency on imperfection)
  - Inputs and outputs- explanations
- IT lesson design platform
  - How to use at least one relevant platform for initial designs (e.g., Canva)
- Clickable Prototypes
  - How to make a clickable prototype (e.g., in PowerPoint)

Research:

- Design-cycles prototype
  - Designing activities
  - Feedback cycles

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### *Expected output*

- Clickable prototypes designed by student groups including explanations and visualizations
- Active feedback- either through notes or direct contact

### *Use for design*

Revision of prototype based on student ideas and feedback

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# 7 References


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# Appendix I.

This section will later be supplemented with a drafted log-book format for facilitators as well as reflection and feedback forms.

# Data Guidelines

Given the numerous partners involved and the need to work towards three clear products, it is important to have clear guidelines on how/what data is collected and how it is shared.

Data in participatory research consists of multiple different parts that can be difficult to differentiate: it can have written, drawn, audio and interpretive components. Session data will include among other things they physical materials produced by participants (brainstorms, sticky notes, problem trees etc.) , audio recordings of the sessions, and log-books or field notes containing the contextual observations and thoughts of facilitators. To navigate this complexity, it is essential that the various partners keep in close contact, as this is the best way to assure consistency and comparability.

During the training, specific time will be dedicated to establishing a timeline for InterVision meetings to share experiences and suggestions as well as for the sharing of data with designers. A recommended format for data sharing is shown below.

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# Appendix II. Activities

(Full activity descriptions to be completed and supplemented at a later date )

HOW TO STRUCTURE A SESSION:

- Pyramid: from specific to more general
- Inverse-pyramid: from general to increasingly specific
- Diamond: specific, to general then narrowing to more specific again
- Hourglass structure: from general to specific and more broad again*

**Adolescents**

*Ice-Breakers and Energizers*

- If you were a fruit
- 1 2 clap
- The last word
- Ball toss brainstorm
- Word combinations
- Doodling together
- Bear-bee-fish

*Getting to know you*

- Personal container
- Where I'm from poem

*Capacity building sessions*

- Research
- Presenting
- Design
- Drawing/poetry/role-play

*Always an option:*

- Guided discussion
- Draw and Write
- Sorting exercises
- Collage
- Research project
  - Interview
  - Questionnaire
  - Observation
  - Online search

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- Graffiti wall/ word-cloud/ jam board

*Topic/Situation Specific*

- Mapping exercises
  - Context mapping
  - Neighborhood safari
- Creative writing exercises
  - Poetry
  - Short story
  - Newspaper article
- Specific drawing exercises
  - Kinetic
  - Body map
  - Hand heart mind
  - prototype
- Exercises of imagination
  - Interview with an alien
  - Perfect world
- Timeline exercises
- Journaling
  - Photo voice
  - Show and tell
  - Vlog style
- Design Jam activities
  - Inspiration cards
  - Storyboard
  - Buy a feature
  - Serious Lego
  - Thumbnail sketching
  - Paper prototyping
  - Crazy eights
  - Hand heart mind
  - Advertisement design
- Feedback exercises
  - Think aloud-s
  - Hand heart mind
  - Rose thorn bud
- Round robin board

*Building sessions*

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Some things require multiple sessions but rarely take up a whole session. Others are useful to combine where for instance a more creative exercise can help provide points for a discussion.

- Build a phase 2 set with some observation/interviews but also in session activities
- Build a phase 3 set like a design jam spread out over time.

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# Appendix III. Recruitment notes

-Select school with high rates of unhealthy behaviors and/or high percentage of families with low socio-economic backgrounds

-collaborate on recruitment strategy with school/teachers e.g., whether it is compulsory as part of a class (difficult as there is a syllabus that needs completing) or voluntary

e.g., host an interactive session to inform youth and spark their enthusiasm for the project- include a Q&A and give them informed consent forms to take home. Prepare a short video about the project for parents and teachers which is sent via the preferred communications strategy of the school.

Children and parents give informed consent.

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