Interoperability case 1: Supporting Chronic Care models

1. **Product vision**

**Situation:**

Conditions that require chronic care, specifically hypertension and diabetes, are highly prevalent. Adherence to medication and lifestyle modification are important to manage these conditions and prevent complications. This requires long-term behavioral change from patients. Care models for chronic care need to support patients to take control of their own health, embedded in an informal and professional care network that can intervene and support when needed.

Chronic care models are currently mostly deployed by either forward looking hospitals and software providers or as part of publicly funded community programs. Both typically operate on closed platforms that need point integrations to collaborate with other systems, including existing HMS’s and upcoming platforms for e.g. education, financing or medicine delivery. This lack of interoperability is a key barrier for in-person care providers to test or adopt innovative solutions, and for virtual care providers to integrate into existing care networks.

**Need for collaboration on a common data set**

Both the individual patient as well as the network of informal and professional caregivers require insights in essential datapoints on disease and disease management status to make informed decisions to manage the conditions:

* Patients:
  + use information on their (self-measured) condition status (ie blood pressure or blood glucose) to motivate health behaviours like medication adherence and lifestyle changes
  + Make informed decisions to seek extra care when self-management is not effective to manage their condition
* Informal caregivers:
  + Use information on condition status of patient to help motivate health behaviours
* Community Health workers:
  + Use information if self-measurement is not taking place to actively follow-up
* Primary/secondary or remote professional caregivers:
  + Use information on disease status to monitor patient and decide if follow-up/medication change is needed
* Providers of digital self-management tools:
  + Use information on disease status and health behaviours to provide automated, personalized digital coaching and behavioural nudges

**Key elements of the data set**

This means several different parties, including patients, benefit from accessing the same data, making this an interesting case for data-exchange. Essential datapoints (from highest to lower relevance) are:

* Blood pressure/blood glucose levels (Frequency 1-2/month at least: can be collected by patient at home or in patient groups, by CHV in community, at local pharmacy, in primary or secondary health facilities)
* Current medication (Frequency depends on medication-changes needed: entered by professional caregiver in primary or secondary facility who prescribes medication)
* BMI (frequency 1/month: can be collected by patient at home or in patient groups, by CHV in community, at local pharmacy, in primary or secondary health facilities)
* Mental health status (Frequency 4x/year: can be collected by patient at home, by CHV in community, at local pharmacy, in primary or secondary health facilities)
* Lab-results: Frequency 4x/year -> hba1c; Frequency 1/year -> kidney function, lipid profile, liver function
* Contacts with professional care providers (either phone or visit) & conclusion of these visits (Frequency 1-12 times/year)
* Other risk-factors: alcohol intake, smoking (Frequency 1/year: can be collected by patient at home, by CHV in community, at local pharmacy, in primary or secondary health facilities)
* Other health behaviours: steps, dietary pattern, etc. (Frequency 1-2/month)

**Key services supported by the dataset**

Different services (or ‘products’) can be made available for this exchangeable dataset, e.g.

* behavioural nudges/automated messaging protocols to patients or doctors based on condition status
* RISK-score algorithm (decision support for clinicians to assess risk of patiënt and required follow-up)
* clinical management dashboards with easy longitudinal insights in BP/blood glucose
* county management dashboards for value-based payments based on population control levels

**Ownership, localization and regulation**

Empowering patients and first line health workers will be critical for the success and societal impact of the solution. Patients should be in control of who has access to their data and health workers should be able to freely choose software and tools that best support them. Key design principles include

* Patients retain actionable control over which data gets exchanged, either directly or delegated to a representative (e.g. patient group leader)
* No vendor lock in: Separation of data from software, ability to switch provider or give access to new emerging services (e.g. telehealth platforms)
* Enabling wide collaboration: Enabling participation of different platforms, both public and private, local and international, open source and proprietary
* Compliance (and in fact demonstrating the application of) country regulation and policy on data exchange and interoperability

**Economic sustainability**Active endorsement by government and county will be critical. However, the sustainability of the solution should not be fully dependent on government or donor funding. A governance and revenue model needs to be developed that can maintain the ‘common services’ involved in this solution, e.g.

* A public-private partnership, cooperation or even social enterprise that acts as neutral third party
* Provides standards, standardized legal arrangements, implementation documentation and support
* Runs (or contracts out) specific common services, e.g. ….
* Has a revenue model, e.g. transaction fee or subscription fee that covers operational costs

1. **Implementation approach**

We propose an iterative development path

* Phase 1: Collaboration of the willing & demonstrate small scale
* Phase 2: Institutionalize & demonstrate at scale
* Phase 3: Promote adoption & support replication

For phase 1, we propose to prioritize speed over perfection and focus on providing a visible, tangible example that supports an urgent use case

* Engage key stakeholders from the start to raise awareness, interest, buy in
  + Ministry of Health, County
  + Christian Health Care association
  + Kenya Cardiac Society, …
  + Safaricom
* Set up an **implementation organization** for the first use case. Keep it small, build a coalition of the willing centered around the concrete first implementations
  + Innovative primary & secondary care providers ie Access Afya, Penda Health, etc
  + Providers of remote care: Baobab Circle, Medtronic labs, access afya, others (explicitly not Luscii ?)
  + Key patient groups (e.g. Nairobi groups through county)
  + Provider of development capacity to build a first, temporary technical solution
  + Sign a MoU and an NDA
* Set up a medical work group
  + Ensure alignment on the objectives in terms of patient experience and outcomes
  + Have clear agreement on essential datapoints to be stored & shared
  + Define the ‘case for change’ that will draw in more (medical professional) partners
* Set up a technical work group
  + Develop the technical design principles, standards, architecture etc.
  + Set up a working structure, role definition, agree on any IP issues vs. open source
  + Quickly develop the first MVP for testing
* Set up an operational work group
  + Include patient representative (e.g. patient group leader)
  + Define key test-settings
  + Enroll patients & providers for testing
  + On-the-ground troubleshooting