COCIR is happy to share its Digital Health Roadmap as a contribution to the Blueprint initiative, championed by COCIR and other digital health stakeholders. This paper offers a high-level overview of a potential technical roadmap for supporting a shift to integrated care. While completing the first two phases is a necessary pre-condition for addressing the subsequent stages successfully, Phases 3 to 6 can progress in parallel.

Any transformation towards integrated care and data sharing is a journey that is deeply grounded in local health and care needs. Indeed, given the complex nature of health and care integration strategies, the boundaries between the six phases may be blurred in practice. In addition, the phases may vary according to country, region and local specificities.

<table>
<thead>
<tr>
<th>PHASES</th>
<th>FUNCTIONS</th>
<th>TECHNOLOGIES</th>
<th>INTEROPERABILITY</th>
<th>DATA PROTECTION</th>
<th>HEALTH TECHNOLOGY ASSESSMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. CAPTURE</td>
<td>All stakeholders in the care continuum capture all necessary data</td>
<td>1. Usability of EMRs, data capture and navigation tools</td>
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<td>1. IT support for the establishment of teams and collaboration between team members</td>
<td>1. Big Data Lakes (from diverse data sources)</td>
</tr>
<tr>
<td>2. AGGREGATE &amp; SHARE</td>
<td>All stakeholders in the care continuum may access, share, aggregate and visualise meaningful data on a daily basis</td>
<td>2. Non-traditional data capture: medical devices, wearables, social media, -omics, Patient Reported Outcomes</td>
<td>2. Semantic Interoperability for data and workflows</td>
<td>2. Distributed and dynamic workflows and associated tools</td>
<td>2. Deep Machine Learning (bottom up)</td>
</tr>
<tr>
<td>3. COLLABORATE</td>
<td>Multidisciplinary teams, including the patient, formal and informal caregivers and processes for collaboration are set up</td>
<td>3. Cloud and Mobile-ready tools</td>
<td>3. Standards</td>
<td>2. Patient-specific care plans</td>
<td>3. Rule based decision support (top down)</td>
</tr>
<tr>
<td>5. SMART CARE</td>
<td>Smart applications routinely support caregivers and patients, taking into account the changing medical, social and operational context. Quality management processes are in place</td>
<td>5. Visual integration of external data sources</td>
<td>5. Patient Reported Outcomes</td>
<td>3. Gamification to engage citizens and patients</td>
<td>5. Big data analytics, including risk stratification tools</td>
</tr>
<tr>
<td>6. POPULATION HEALTH</td>
<td>The acquired experience and insights trickle down to health care experts and health policy makers, enabling them to further focus on outcomes and adopt a VBHC approach</td>
<td>6. Data sharing platforms</td>
<td>6. Telehealth</td>
<td>4. Impact assessment tools</td>
<td></td>
</tr>
</tbody>
</table>
CAPTURE PHASE 1
AGGREGATE & SHARE PHASE 2
COLLABORATE PHASE 3
COORDINATE PHASE 4
SMART CARE PHASE 5
POPULATION HEALTH PHASE 6
NORMALISED PATIENT-CENTRIC DATA CAPTURE

During this phase, the focus for all stakeholders in the care continuum is to capture all necessary data. Most health systems are currently in the midst of this phase and are likely to remain there for some time. Currently, a substantial proportion of resources are being spent on collecting health and care data. However, this data is usually stored in different information silos rather than generating a comprehensive knowledge base for the patient’s care.

Therefore, the overarching goal of this phase should be to ensure that all relevant clinical and operational events are properly captured in reusable formats. This will enable a transition from episodic data collection to lifelong records in Phase 2.

From a technological perspective, the focus should be on the following elements:

- **Enabling** data input and navigation through cloud and mobile-ready tools.

- **Kick-starting** the normalisation process by capturing patient-centric data in a standardised format, with parallel progress in structured data entry and Natural Language Processing-enabled data capture. Normalising the collected data using a common coding scheme, such as LOINC, ICD or SNOMED, will ensure the interoperability and meaningful use of the data. Professionals should also be able to use Natural Language Processing (NLP) tools for auto-coding purposes, enabling quick and user-friendly structured data entry. The data collected should be stored in systems that are built with patient-centric, rather than administrative-centric, approaches. This should be optimised for the operational and financial reporting features offered by most of today’s Electronic Medical Records systems.

- **Facilitating** both the inclusion of clinical data and of data generated through non-traditional health information sources. These include vital signs sensors, -omics, mHealth apps, social media and patient-generated data. The patient is both a key stakeholder, actively engaged in their own care, as well as a primary source of data. Therefore, an effective IT system must allow them to contribute their own health data, via a variety of channels including forms, questionnaires and methods for Patient Reported Outcomes. The system must be capable of accepting these types of data entry and flag them clearly and unambiguously as patient-generated data.

- **Addressing usability.** One of the keys to successfully deploying any new IT infrastructure is to address user design and usability early in the design process. There needs to be both smart and kind (user-friendly) applications in all the phases of the Roadmap. This is particularly relevant for IT systems supporting integrated care, as the solutions deployed need to suit both health and care professionals as well as the non-professional users such as citizens, patients, family members and carers. None of the current standards of usability meet these requirements; therefore, adopting an iterative, user-driven design and co-creation approach would be the ideal way forward.
AGGREGATING AND SHARING DATA IN A LONGITUDINAL PATIENT RECORD

While Phase 1 focused on data capture and normalisation, the objective of phase 2 is to enable all stakeholders in the care continuum - including the patient - to share, aggregate and visualise meaningful data on a daily basis. There will need to be health data governance mechanisms in place to allow for data use and sharing. These should organise and provide access to health data while safeguarding patients’ privacy and data protection rights.

From a technological perspective, this phase should focus on the following aspects:

- **Enabling** technical visual integration of the systems that the stakeholders in the health continuum will use routinely. This means fully integrating the shared data into existing IT infrastructures and applications, thus allowing health and care professionals to use the available data and tools in their daily practice. (e.g. i-frame embedded views or using APIs). This will require data-sharing and interoperability between existing IT infrastructures. The data will need to be accessible in multiple formats and via multiple platforms to meet differing user needs (admin, clinical, patient, carers, etc.).

- **Allowing** a common visualisation of assigned care plans. Although many institutions have already adopted care pathways, there is no common standard, making them difficult to share. Agreeing on a common care plan and sharing it as a document, even in pdf format, would already be a productive start and will begin to pave the way for collaboration.

- **Adhering** to health interchange standards along with richer semantic standards. Many of the current standards are formalising concepts such as diagnoses but not the relationships between these and the context in which they were captured. In addition, as the goal of a single standard seems unreachable, there should be greater emphasis placed on ensuring interoperability between the various standards in use.

- **Implementing** healthcare communication standards (HL7, DICOM, FHIR), IHE profiles and Continua guidelines for exchanging health information and integrating the various information silos.

- **Using semantic technologies and NLP** to extract meaningful information from non-structured data. In Phase 1, we suggested using NLP to capture new data; during this Phase, we recommend using it to exchange the huge amount of existing non-structured data.

- **Deploying** a global identity management solution to ensure that all stakeholders involved (patients, carers, health and care professionals) have a unique identifier.

- **Rolling-out** patient consent management systems, allowing patients to grant consent for sharing their personal data outside the institutions where it was originally collected.

- **Providing** information on data provenance. It is extremely important to always know exactly where shared data is coming from and who has entered it.
CARE TEAM COLLABORATION

Based on the sharing of data and care plans, Phase 3 will focus on achieving widespread care team collaboration, involving the patient and informal caregivers as well as health and social care professionals. As a result, this phase will also empower stakeholders to migrate from delivering healthcare to delivering holistic health and social care and well-being.

During this phase, it is important that case and care managers (or other professionals with a coordinating role) have the tools to effectively manage the processes of the care team, that will include the patient/citizen and caregivers, according to the different roles identified.

Although there are existing examples of care team collaboration systems, these have failed to address the objectives set out in the earlier phases. As a result, they do not truly assist the care team in making shared decisions, coordinating care and sharing data.

From a technological perspective, this phase should focus on the following aspects:

- **Deploying** well integrated tools for team collaboration, both technical and visual, across the health and social care settings based on social media and collaborative principles.

- **Enabling** bi-directional and instantaneous communications between all settings, including healthcare, social, long-term care settings and home. This will make information timely available across the care continuum without information gaps or duplications.

- **Incorporating** the use of social media technology for point to point communication (video and audio connections as well as messaging).

- **Expanding** the data exchange standards already supported to include data collected in social care settings.

- **Assessing** teams’ efficiency, tracking outcomes and use of resources and pursuing clinically proven best practices.
CARE COORDINATION AND INTEGRATED CARE

Genuine health management at individual patient level can begin in Phase 4, based on the collaborative tools and sharing data and care plans. This can begin with healthcare and evolve into all-encompassing care coordination, including wellness, social care and support for independent living.

A key focus during this phase will be in empowering and encouraging people to manage in their own care and wellbeing. The emphasis will expand from patients who require medical care to individuals needing holistic care and support. Integrated Care will create a shift from delivering “passive” health and social care services to making individuals “active” partners in managing their own health evolving into a genuinely person-centric approach to care delivery. In an ageing population, many more older citizens will increasingly have more than one medical condition and require multidisciplinary and multimorbid care plans. During this phase, care will be patient, rather than disease centric, taking into account personal preferences and lifestyle.

From a technological perspective, the focus should be on the following aspects:

- **Enabling** virtual sharing of care plans among all care team members. The care plan should be holistic, describing both clinical and non-clinical needs and services, including both home and community-based care. As a bare minimum, the available IT solution should allow team members to electronically view information directly relevant to their role, easily identify roles and responsibilities within the team and to update other members on developments. The care plan itself will be an agreed set of tasks, which can be assigned to - and by - care team members, including the patient and care givers.

- **Deploying** IT systems that support dynamic, distributed, citizen-specific and integrated (clinical + social + informal) care workflows.

- **Ensuring** visual and technical integration of IT systems allows care team members seamless access to the care plan across all settings, including home and community-based environments. Integration with the broader societal context of connected IT systems and apps should be addressed (smart cities, home automation, wellness, transport, etc.) at a later stage, adopting a step-wise approach. This should deliver integrated applications that are specifically and dynamically adapted for the different users, use cases and contexts with the appropriate access rights.

- **Using gamification and apps** to help patients and care givers increase treatment adherence through behavioural change therapies and other psychological motivational elements, improving long-term outcomes.

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SMART APPLICATIONS LEVERAGING ANALYTICS AND COGNITIVE REASONING

During this phase, cognitive computing and artificial Intelligence will take off in the form of decision support systems integrated into dynamic and patient-specific workflows. This will be based on the shared, multi-modal and enriched (big) data established during the previous phases. Caregivers and patients will routinely look to smart applications for support, taking into account the constantly changing medical, social and operational context.

Patient related data, captured from the various data sources, will be processed to provide new knowledge and insights. These will feed into clinical and non-clinical applications to reach the quadruple aim of improving health outcomes, identifying gaps, reducing system waste and improving patient/citizen experience as well as health and social professionals’ experience. The underlying technologies and methods for achieving this are a combination of cognitive reasoning and analytics (e.g. deep learning) along with mathematical and statistical models. The quality of these models will depend greatly on the quality of the data available.

This will require progress in ‘data lake’ infrastructure, deep machine learning and clinical decision support algorithms that are accepted by the health and care community. Just as patient-level clinical data is shared between stakeholders, so the necessary medical knowledge and guidelines and the ICT services will require a broader infrastructure and service delivery platform to enable the provision of clinical services (clinical decision support, diagnostic support, etc.).

From a technological perspective, the focus should be on the following aspects:

- **Advancing** deep machine learning, imaging analytics, formalising and sharing of medical knowledge, statistical evidence and mathematical models.
- **Sharing** algorithms and high-level clinical decision and workflow generation ICT-services via service ecosystems that go beyond mere data-access services.
- **Providing** smart alert services based on integrating clinical decision support in treatment and preventive settings, striking a correct balance between over and under-alerting to prevent alert fatigue.
- **Developing** self-adapting and contextual user-specific user interfaces.
- **Enabling** controlled access to ‘data lakes’ of relevant clinical data that comply with an agreed legal framework and with proper pseudonymisation of sensitive data.
- **Addressing** the clinical and technical challenges linked to the coverage of multiple diseases. This involves dynamically generated care plans to deal with the complexity of co-morbidities.
- **Personalising** care delivery by analysing large amounts of data (including -omics data).
POPULATION HEALTH MANAGEMENT

The acquired experience and insights will trickle down to health care experts and health policy makers. This will close the loop at society level, improving health care systems. This phase will require re-structuring reimbursement and health financing systems to substantiate the efficiency gains at system level and to provide proper incentives for all stakeholders to fully support the necessary changes.

From a technological perspective, the focus should be on the following aspects:

- **Deploying** analytics systems for performing population risk stratification. This will enable targeted prevention interventions that address the specific risks facing specific population groups, for example high-need patients at risk of hospitalisation.

- **Enabling** large scale access and analysis of large amounts of multi modal data. This will allow to extract population-wide epidemiological trends to measure the efficiency and value of health policy measures and new technologies (HTA: Health Technology Assessment).

- **Disseminating and sharing**, in a computer-readable way, the findings and evidence from statistical analysis of big data.

- **Develop value-based** reporting models, where agreed targets are the driver for all stakeholders.
As Blueprint Champion and partner of the EIP on AHA, COCIR is committed to working with other organisations to advance integrated and patient-centric care models, building multi-stakeholder partnerships for advancing integrated and patient-centric care models.