ELDAC

End of Life Directions for Aged Care

Health IT in Australian general practice: opportunities and challenges

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Introduction

The global population is aging rapidly. It is estimated that over a quarter of the world's population will be aged over 65 by 2050 (Wilson et al. 2016). Similar trend is observed in Australia, with over 15% of Australians aged of 65 years, 20% of whom live some form of disability (1). While Australians are living longer, their later years are impacted by chronic life limiting conditions such as cardiovascular diseases, cancer, and neurological conditions (1). Older people are the highest consumers of healthcare services. Almost 30% of all general practice attendance in Australia are for older people (2). As more and more older people continue to live and age in the community, general practitioners are ideally placed to initiate conversations of palliative care to the aging population with complex life limiting conditions.

Palliative care is defined as person and family-centred care provided to those with chronic life limiting conditions with little to no prospect of cure, where the aim is to optimise quality of life (3). The benefits of early implementation of palliative care for those living with and dying from chronic illnesses (and their families) is well documented in the literature (2, 4). While a small proportion of Australians are provided End-of-Life (EOL) care by specialist inpatient or community palliative care services, most EOL care activities are carried out by generalist providers such as General Practitioners (GPs), hospitals, community health services and residential aged care facilities (5). As the need for EOL care continues to grow together with the aging population, more demands are being placed on GPs to adopt palliative approach to care. In addition to preventative and general care, GPs are increasingly expected to identify patients who might benefit from EOL care in a timely manner; and then provide holistic end of life care including symptom relief, psychosocial and spiritual needs, and preservation of patient dignity and autonomy (6). Given this reality, there is scope in exploring the if health technologies could offer any support in the planning and provisioning of palliative care in the general practice setting in Australia.

This report attempts to explore the opportunities and challenges of health IT integration in the Australian general practice setting by: (i) describing the current health IT infrastructure, policies and initiatives relating to health technology (section 1), (ii) evaluating the international peer reviewed literature on technology use in the general practice setting (including palliative care) (section 2), and (iii) presenting a case study of a well-integrated health IT ecosystem of Portugal (section 3).

Section 1: Technology ecosystem and policies in Australian general practice

General Practice in Australia

Primary healthcare in Australia is largely provided in the General practice setting. General Practitioners provide range of healthcare services to people living in the community including preventative care and the diagnosis and treatment of illness and injury, and appropriate referrals to tertiary and specialist care services. Funding for the general practice setting is provided by the Australian Government through Medicare and the Department of Veterans Affairs (DVA).

In addition, the government also provides additional funding to general practices via incentives such as the Practice Incentives Program (PIP) and Primary Health Networks (PHNs) to improve the quality of general practice services across Australia. General practices also get some funding through insurance schemes and patient contributions (7)

Use of digital technology in the Australian General practice setting

Computers are commonly used in Australian general practice. Over 97% of GPs use computers for clinical purposes, and over two-thirds (70%) using electronic medical records exclusively. The Royal Australian College of General Practice (RACGP) outlines that the use of technology in the Australian general practice setting primarily relates to information management (8). As such, GPs use computers to manage clinical and non-clinical information. In the context of general practice, information is collected, stored, and shared; while this information is also utilised in clinical decision making (8). General practices use an online portal developed by the Australian government called Health Professional Online Services (HPOS) to manage services, payment, and other government programs including the My Health Record. Management of patient's clinical data, however, is done using one or more Clinical Information Systems (CIS). Various specialised computer softwares are available to general practices for clinical data collection, storage, and transfer.

Understanding the foundations of electronic health data

The electronically managed clinical data is commonly referred to as 'electronic health record', or 'electronic medical record'. However, these terms denote two different things.

An *Electronic Medical Record* (EMR) contains information that is created and resides within **a single healthcare organisation** (such as a clinic, medical centre, or a hospital) (9). While an *Electronic Health Record* (EHR) contains information that can be managed, added to and accessed across **multiple healthcare organisations.** It is important to note that both EMRs and EHRs are managed by Professionals/clinicians or care providers. On the other hand, *'Personal Health Records (PHR)'* also known as the Australian Government's *My Health Record (MHR)* contains the same types of information as EHRs—diagnoses, medications, immunizations, family medical histories, and provider contact information—but is designed to be set up, accessed, and ***managed by patients***. Australian Patients/consumers can use MHRs to maintain and manage their health information in a private, secure, and confidential environment. MHRs can include information from a variety of sources including clinicians, home monitoring devices, and patients themselves

Electronic Health data in the Australian general practice context

General practices in Australia can access a patient's My Health Record via: the national provider portal (HPOS) (view information only) or from their CIS (upload and/or view information). There are 50 CISs that offer the ability to access, input and download the My Health Record.

The digital health architecture across health sector in Australia

One of the first government level initiatives toward digital health in Australia was establishment of the National Electronic Health Transition Authority (NEHTA) in 2005. NEHTA aimed to accelerate the adoption of electronic health information systems across Australia. Its strategic plans included interconnected within the healthcare sector, and development of specifications, standards and necessary infrastructure. However, over a decade and half after the establishment of NEHTA, the primary and tertiary care setting still do not have a seamlessly interconnected health information system.

General practices and hospitals in Australia use different electronic data management systems. Hospital within same 'health network/district' may use the same system allowing inter-hospital data sharing. However, a common portal for collecting, storing and managing patient data across the general practice and hospital setting does not exist in Australia. Discharge summaries of patients are often sent to their GPs as fax or posted mail.

The Australian Digital Health Agency was established in 2016 to ensure relevant national standards and infrastructures are in place for appropriate integration and use of digital health in across Australia. The national infrastructure uses the Health Identifier and PCEHR System (HIPS) to enable seamless integration of digital health systems with national digital health infrastructure services, such as the Healthcare Identifiers Service, the My Health Record system, Secure Message Delivery systems and National Directory Services. The figure below portrays the plan for Australia's digital health connectedness.

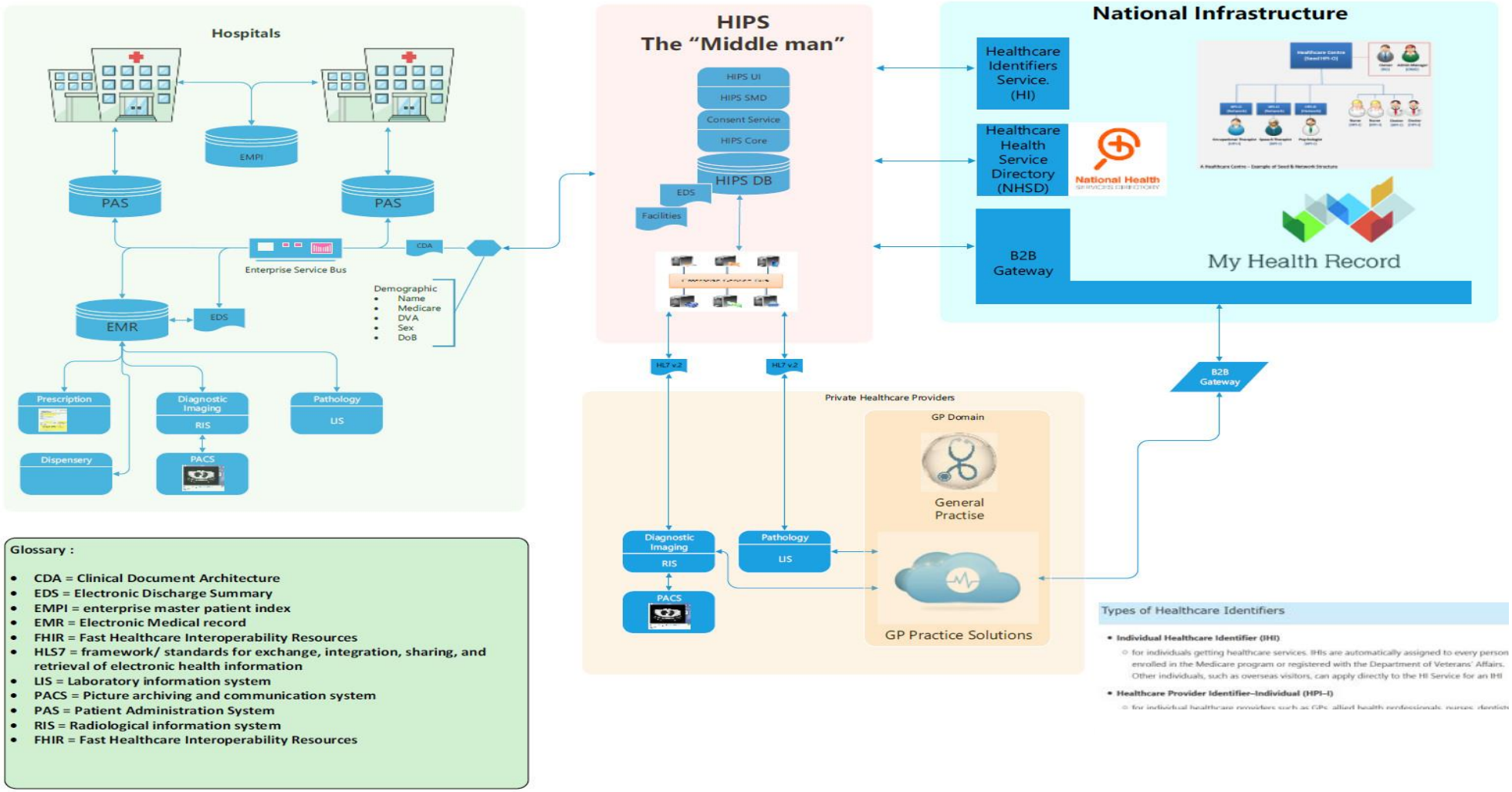

Figure 1.1 Australian digital health connectedness plan

In the latest move to increase the adoption and use of digital health systems across healthcare sectors, the Australian Digital Health Agency launched a new digital health strategy in 2018 titled *Safe, Seamless, and Secure: evolving health and care to meet the needs of modern Australia* (10).

The National Digital Health Strategy has seven priority areas outlined in the 2018–22 plan and provides a clear plan for collaboration and action to improve health outcomes for all Australians. These priorities are:

1. My Health Record system,
2. Secure messaging,
3. Interoperability and data quality,
4. medication safety,
5. enhanced models of care,
6. workforce education, and
7. driving innovation.

The priorities are operationalised through a Framework for Action (11) that identifies required activities and the roles of stakeholders. The activities encompassed within each of the priorities are shown in the figure 2. GPs and health care IT industry are expected to partner with the government in achieving these priorities.

Figure 1.2 National digital health priority activities

Incentive for GPs to engage with digital health

There were just over 6,300 GP practices in Australia in 2017 (7). Over 97% Australian GPs use computer for their work, 70% of whom use electronic clinical documentation. While practice specific collection, storage and use of patient's clinical data is a common practice, there is a policy level drive for broader adoption and use of My Health Record as the centre point for information collection, storage and sharing.

The Department of Health funds the Practice Incentives Program which encourages and supports the general practices to enhance their capacity, provide better quality care and improve patient outcomes (11) . The *eHealth Incentive* under PIP aims to encourage general practices to keep up to date with the latest developments in digital health and adopt new digital health technology as it becomes available. Under this incentive general practices can receive up to $12,500 per quarter if they meet the following criteria:

1. Integrate the following three identifiers within their Clinical information system:
    a. Health Professional Indicator for organisation (HPI-O);
    b. Health Professional Indicator for Individual GPS (IHI-I); and
    c. Individual Healthcare Identifiers for patients (IHI).
2. Apply for and obtain the 'National Authentication Service for Health (NASH) Public Key Infrastructure (PKI). Within four weeks of obtaining the NAASH PKI, have a product with secure messaging capability installed. might have to use auxiliary software product.
3. Record patient diagnosis using standard medical vocabulary such as ICD10-AM, SNOMED-CT.
4. Send majority of prescriptions electronically to Prescription Exchange Service (PES). - might have to use auxiliary software product.
5. Access, use of, and upload to the My health record
    a. Use a compliant Clinical software system to access and upload to the MHR system.
    b. Apply to participate in the MHR system.
    c. Must upload shared health summaries for a minimum of 0.5% of the practice's whole Patient Equivalent count of patients per payment quarter

Meeting the eligibility criteria 1, 2 and 3 (partially) require actions to be taken by GPs/practices. Meeting eligibility 3 partially, 4 and 5 rely on technical capability of the CIS used at the practice (by the GP).

GPs/Practices should obtain the 3 identifiers (Eligibility criteria 1), obtain NASH PKI (eligibility criteria 2); and ensure their clinical data is coded using standardised medical vocabulary. In addition to this, the GPs/Practice should use appropriate clinical information system(s) and other auxiliary software(s). For example, currently there are multiple clinical data management softwares that allow its users (clinicians) to access and/or update the patient's My Health Record (eligibility criteria 5.a). Some well-known providers serving the general practice setting include Medical director, Best practice, Communicare (Telstra health), and Zedmed. These four systems also meet eligibility criteria 1 (integration of the HPI-O, IHI-I, and IHI). However not all CIS meet multiple criteria which could necessitate a practice having to use/subscribe to multiple systems/softwares. The only provider offering a suite of solutions meeting all the eligibility (1-5) is the Telstra health's suite of solutions. General practices using any other software would have to engage with more than one IT company.

CISs in use within general practices

The three most used CIS in Australian general practice are Medical Director, Best Practice, and ZedMed, with an estimated 90% coverage. These softwares offer various functions, including but not limited to: Calendar and scheduling, financial management, patient management, integrated clinical tools, and practice management support. As interconnectedness to (and via) MHR seems to be a national priority in the digital health landscape, there is an understandable disinterest among funders, policy-makers and software companies in enhancing the function of CIS in improving care processes and outcomes. It is unclear if any of these CIS offer the functionality of comprehensive assessment and follow-up relating to end-of-life/palliative care planning.

ICT in health and the COVID-19 pandemic

As the cases of COVID-19 started climbing rapidly in Australia in mid-end of March 2020, the government enforced strict social distancing measures to control the spread of this highly contagious virus. To ensure the general public is not debarred from receiving the healthcare they need in the primary care sector during these times, the government brought in a range of new telehealth measures allowing various health professionals to bulk-bill telephone or video

mediated consults. While various structural and systems level challenges in implementation of the nationwide telehealth approach was anticipated, the Australian health IT sector has been swift and agile in trying to meet the new telehealth and COVID-19 related demands of the sector. Various telehealth solutions have been developed to support health professionals who are expected to provide efficient and timely care to patients across the community and aged care setting. Practice management software providers servicing the general, allied and/or specialised practices (including: Medical director, MediRecords Best practice, Shexie platinum, Cliniko, Global Health) have developed integrated telehealth capabilities to enable activities such as appointment management, one click entry to meetings, screen sharing, patient facing app for pathology request forms, medication and remote result viewing. Similarly, some IT companies out of the practice management scope have developed stand-alone and/or 'plug-in' style software (depending on the practice management software) that could be used for purposes such as: remote symptom monitoring of COVID-19 patients (CareMonitor), comprehensive telehealth platform (Coviu), and patient led virtual consult booking system (AutoMed).

The way how the health IT industry has risen to occasion shows that the industry is capable of developing and implementing meaningful software/systems (almost instantaneously) to meet the needs of the healthcare sector. Such ability of the healthcare IT industry indicates the potential for technology to integrated across to other aspects of primary healthcare such as end-of-life and palliative care. While more significant proportion of Australians continue to die in the community setting, palliative care needs to be an integral part of general practice care. The ability of the health technology industry for speedy adaptation of existing software/platform including the development and implementation of plug-in applications, presents itself as an opportunity to be explored in the realm of palliative care provision in the general practice setting.

Section summary

The above section outlined the infrastructure, policies and initiatives driving the health technology use and adoption in the Australian general practice setting. Emerging technology developments that occurred to accommodate the COVID-19 pandemic in Australia was also presented. There seems to be a systems level push to promote interconnectedness across all healthcare setting via the patient-controlled MHR in the front end, and in the backend via the HIPS system. While the Department of Health is encouraging general practices to adopt health IT systems that allow seamless interconnectedness across various care settings, the

CIS companies are simultaneously increasing their capacity to facilitate integrated and interconnected healthcare. It seems that the currently in Australia, the government level focus, and the subsequent health IT industry level priority, is interoperability and interconnectedness. While this indicates an opportunity for development and deployment of technologies to facilitate palliative care in the general practice, the complex health IT landscape presents as an additional challenge to the complex enough process of developing and deploying a novel health technology. It is also important to consider what kinds of technologies have already been developed and tested in the general practice setting.

The following section present the review of peer-reviewed literature reporting development or testing of any health IT (including palliative care) in the general practice setting.

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Section 2: Peer-reviewed literature on technology and general practice

Method

A search strategy was developed by the study team with further input from specialist health librarian (RD). Searches were conducted in Medline and Scopus databases in March 2020 using a combination of free-texts (as keywords) and MeSH terms (Refer appendix 1). Identified citations were exported to Endnote reference management program. English language peer reviewed primary research, or product development, papers were considered for inclusion if they reported the use of technology to facilitate care in general practice or primary care setting.

A total of 324 unique articles were identified, 250 of which were excluded following title and abstract review, leaving 74 papers for full-text review. Out of the 74 papers 46 were excluded following full text review as they did not meet the eligibility criteria, leaving 28 papers for inclusion in this review.

Result

This review included 28 studies undertaken in general practice setting describing the use of some form of health information technology in the context of patient care. Broadly, the international literature suggests permeation of health information technology across the general practice setting in various forms such as: clinical decision support, electronic medical record, medication management, risk/needs identification, and remote monitoring. The studies tested various approaches to accessing, using and interpreting health information including: electronic health record (n=9) (1-9), dashboards (n=9) (10-18), clinical decision support system (n=6) (19-24), patient clinician data sharing models (n=2) (25, 26), and apps (n=2) (27, 28).

The studies explored the use of technology in relation to varied areas and/or population of interest, including chronic illness (n=9) (1, 6, 13, 17, 21, 25-28), medication management (n=4) (12, 16, 18, 24), EOL and/or palliative care (n=3) (2, 7, 8), general care activities (including patient follow-ups) (n= 3) (14, 15, 20), mental health (n=2) (3, 9). Seven (n=7) (4, 5, 10, 11, 19, 22, 23) studies did not related to any specific population or disease condition. These studies reported on topics such as development or usability testing of a system/tool

(n=4) (5, 10, 11, 22, 23), general care coordination (n=1) (4), and qualitative evaluation of potential benefits of a clinical decision support system (n=1) (19).

Majority of the studies in the area of chronic disease management (n=5) evaluated the use of technology in early identification and assessment of disease symptoms and risks (1, 17, 21, 27, 28). While others, utilised remote monitoring either via sensor based devices (25), or via carer report (26) for chronic disease management. The three quantitative studies on medication management (12, 16, 18) looked at the role of integrated dashboard to facilitate medication safety (12, 18), and guideline specific (appropriate) prescribing (16). The qualitative study explored clinicians' views regarding the benefits of a clinical decision support system in facilitating heart failure medication management (24). Clinicians of this study believed such system to be value adding if it offered non-interruptive alerts, clinically relevant and customisable support, summarised pertinent information, and improved workflow.

The studies reporting broadly on development and evaluation of technologies (n= 5) explored topics including: patient follow-up (10, 11), usability testing (22), development process and aspects of interoperability (23). The fifth study was a systematic review exploring the use of electronic health records in primary care. Among the two studies focussed in the area of mental health, one (3) evaluated the use of electronic medical records for documentation of behavioural health interventions and general primary care information, while the other (9) reports the development and implementation of a software 'plug-in' system that collected data on epidemiology and management of common mental health conditions.

There were three studies that specifically focused on technologies relating to palliative care (2, 7, 8). Two of these studies were conducted in the USA (2, 8), the third was carried out in the UK (7). The summary of these studies is presented in table 1 below. Briefly, the studies primarily focussed on early identification of palliative care needs (7) and/or Advance care planning (2, 8). The study by Bose and colleagues (2) reports on a mixed method study involving primary care patients and clinicians to develop and test a framework for advance care planning. A framework for ACP was developed and deployed in the participating service's patient facing health platform (MyChart). Patients were invited for usability testing of the platform and interviewed. While participants found the content and structure of the framework easy to navigate, they voiced difficulty in successfully using the technology (MyChart), and some discomfort in answering the questions included and wishing for

clinician's follow-up (2). The study in UK developed and evaluated a simple EHR search tool that aimed to identify patients who might benefit from early initiation of palliative care. The search algorithm was informed by the Supportive Palliative Care Indicators Tool (SPICT), and the identified list of patients were considered clinicians against the 'Surprise question' for further palliative care suitability assessment. This plug-in style search was found to be feasible to develop and integrate into an existing EHR and be useful for early identification of patients who may benefit from palliative care. The third study focussed on palliative care (8) described a multimodal initiative aimed at initiation of ACP discussion and documentation. The multimodal intervention included staff education and training, a dedicated ACP nurse liaison, and EHR modification. The EHR was modified to: collect data on whether end of life discussions were carried out; store scanned ACD document; and a smartform form easy retrieval of any ACP related notes (8).

Table 2.1: Summary of studies reporting on palliative care technologies

Author/ Country	Population	Study aim	Study procedure	Study outcomes/findings
(Bose-Brill et al. 2016) USA	Patients with 1 or more chronic disease aged over 50 years. Physician-Primary care provider	To develop an Advance Care Planning (ACP) framework to be used in tethered personal health record to be used by primary care patients and accessed by their GPs.	**Phase 1**: Focus groups with patients (4 sessions) and primary care physicians (1 session) to elicit their preferences for an advance care planning framework delivered over electronic health record. **Phase 2**: Following the development of the framework, cognitive interviews were carried out with primary care patients. These interviews adopted "think aloud" approach to seek participant feedback on content, structure, and layout of the ACP framework.	Focus group participants found the site-specific online patient facing health portal (MyChart) to be helpful communication tool. They wanted the ACP framework to have clear language, allow customisation, and provide options to qualify and disqualify preferred decisionmakers. Participants reviewing the ACP framework over MyChart recommended rewording of the questions, need for introduction to the framework, desire for follow-up and discussion and some felt discomfort answering the questions. *Physician focus group result not reported.
(Mason et al. 2015) UK	Primary care patients with chronic disease.	To describe the development and testing of a computerised search of primary care records in routine clinical practice as a tool to improve patient identification for a palliative care approach.	**Phase 1**: Development of an algorithmic EHR search mechanism to identify patients whose record include clinical indicators from the SPICT. **Phase 2:** Initial testing of the search system by 10 general practices. GPs asked to run the search and consider the resultant list of patients for discuss in their multidisciplinary team meeting against the "surprise question" **Phase 3**: Five general practices implemented the search system and actioned it at least a few times every 10-15 weeks, reviewed the results at their team meetings, and considered 3-5 patients for palliative care planning **Additional:** Interviews were conducted with GP participants of phase 2 and 3 to elicit their perception of usefulness of the search system.	It is possible to run a search of existing EHR to identify patients with deteriorating health/palliative care needs. The patients identified by the search were most commonly commenced on an anticipatory care plan (53%) or added to a 'palliative care register by the GPs. The search provided an additional resource that could be integrated into routine clinical practice without requiring any new software or hardware. However, some GPs expressed concerns about this approach which could potentially increase their workload without a direct and obvious benefit to their patients.

(Rose et al. 2019) USA	36 primary care practices (n=19 intervention group, n=17 comparison group)	Introduction of a multimodal initiative named 'Conversation of a Lifetime' aimed at enhancing timely initiation of Advance care planning, and development and documentation of Advance directives in primary care setting.	**Phase 1**: The intervention included four components: communication coaching for physicians and mid-level providers, training nonphysician ACP facilitators, ACP nurse liaison for support, and EMR enhancements. EMR enhancements were designed and implemented at the patient level. A simple checkbox was added to provide a data source to track the number of conversations initiated and documented system-wide **Phase 2**: All components from Phase 1 and a best practice alert in the EHR. The alert was designed to help providers identify patients most appropriate for initiating ACP. Total of 12 practices agreed to participate in Phase 2. **Phase 3**: After the intervention period, ACP conversations continued to be initiated and tracked.	In the 31 months Phase 1 period, 7200 unique patients had ACP conversations initiated and documented in the EMR. When ACP was initiated, an average of 29% of conversations led to an AD in the chart. Rates of AD completion were similar in the intervention and comparison practices. In Phase 3, in 2017, after the study period, 7589 new ACP conversations were initiated. *Important to note that the technology aspect of this intervention was heavily supported by robust staff training and education program, and ACP nurse liaison.

ACP: Advance care planning; AD: Advance Directive; EHR: Electronic Health Record; EMR: Electronic Medical Record; GP: General Practitioner; SPICT: Supportive & Palliative Care Indicators Tool;.

Discussion

The globally aging population has led to simultaneous increase in the burden of chronic disease. Increasing patient numbers, complex symptom management needs, and limited resources has led to growing interest in development and utilisation of digital technologies to augment the chronic, aged, and palliative care provisioning process. This interest is reflected in the general practice research landscape where numerous studies report development and evaluation of various technologies in this setting to facilitate care planning and provisioning process (3, 13, 19, 21, 27). While interest in use and modification of EHR in general practice appears to be the most commonly studied topic (1, 4, 7), technologies relating to clinical decisions support (19, 20, 22), app use (27, 28), and even artificial intelligence (29) is garnering research interest. Despite this growing interest, technologies specific to palliative care planning and provisioning in the general practice setting seem uncommon. This review identified only three studies that specifically evaluated use of technology in the general practice setting for palliative care planning or provisioning (2, 7, 8).

While literature relating to technology mediated palliative care in general practice seems sparse, there is growing interest in such approaches out of the general practice setting. Early identification of patients' palliative care needs vis EMR data manipulation in hospital setting are most commonly reported (30-33). A review of literature and apps conducted by Lau and colleagues focussed on evaluating evidence, practice and technological developments aimed at supporting cancer patients (34). This review reported that while interest in integrating technology to support end of life care in cancer patients is growing, most studies are limited to narrow range of supportive roles. This review also reported that most palliative care apps offer features such as teleconsultation, patient education, and guidance to clinician which could be valuable in extending care those who have limited direct access to specialist palliative care services (34). The literature also reports the use and evaluation of communication and collaboration technology in specialist palliative care and oncology setting (35).

Conclusion of the review

While current evidence in the area of technology mediated palliative care in general practice setting seems spares, literature from non-general practice setting indicates the potential to develop and use technology led interventions to support palliative care in general practice setting.

Section summary

This review did not find any peer reviewed literature referring to use of health IT in the area of palliative care in general practice Australia. The finding indicates an opportunity to explore the role of health IT in facilitating palliative care in the Australian general practice setting. However, this finding should be interpreted with caution because not all technology development and deployment activities are published in peer reviewed journals. While our findings reveal lack of robust methodological studies reporting on palliative care specific technology for Australian general practice setting, there is a possibility of small-scale work that might have been carried out in this space. Future endeavours aimed at developing palliative care technology for Australian general practice should consider the findings of this review while also exploring the technology specific needs of Australian GPs in the context of timely and appropriate palliative care planning and provisioning. Careful consideration of the broader (systems level) context such as: government policies, funding initiatives, and health technology priorities; as well as priorities and capabilities of the health IT sector is also essential.

The following section presents a case study of an interconnected and interoperable health IT ecosystem of the Portuguese healthcare system.

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Section 3: Portuguese Reality: Report on information and communication in palliative care

Introduction

The rapid and continuous growth of new technologies has allowed them to become integrated into everyday life, shifting from being ‘rare’ to becoming ‘normal’ in a matter of a decade or so. In the process, the way people live and work continues to change. As jobs become automated, new technology-driven jobs emerge, and new communication methods transcend time and distance (1; 2).

As World Health Organization (WHO) spokesperson mentioned in 2007 “Patient safety is a serious global concern, with successive studies showing that errors occur in around 10% of hospitalisations. Improving patient safety depends on effective and sustained policies and programmes being in place within every healthcare setting including the home, community and hospital.” (3). Digital health not only can information and communication technologies (ICT) help collect data which a health organization can then use to learn from and eliminate safety issues, but it can also improve patient cantered approach by enabling different and distant institutions to safely and efficiently communicate with which other in regards to one patients’ health problems.

Portugal has been involved in telepath since 1990s and has been scaling up good examples and maximising their impact through ICT health changes. The promotion of the use of ICT as an integral part of the National Health System’s reform processes is a political priority for health in Portugal. There is a clear agreement among all national stakeholders that the convergence between technology and health care brings indisputable benefits, namely faster and easier access to health care and information; greater control by users over their health information, as well as greater efficiency in the provision of care and the development of clinical and scientific research. Thus, the successive governments of the country have made efforts for an effective digital transformation of health in Portugal. The private health sector has also been active in leveraging eHealth (4). Besides promoting a universal digital health, the aim is also to educate healthcare professionals and citizens in digital health.

Like Micaela Seeman Monteiro, director of the National Telehealth Centre, said: “Only through a national strategy, with a clear overview of the goals to be achieved and supported by policy-makers, managers, professionals, patients and caregivers will it be possible to turn

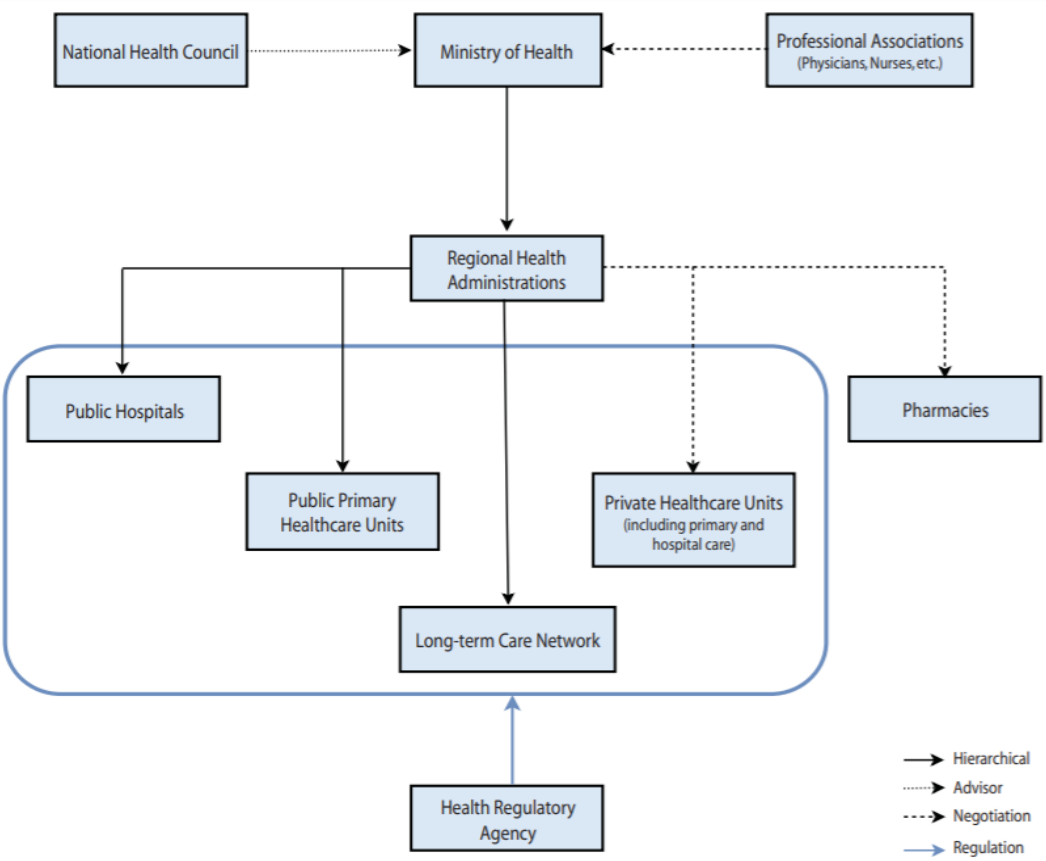
initiatives into an articulated and synergistic system, which is more than the sum of its parts." (5).

Portuguese National Healthcare System

The first social security law in Portugal was enacted in 1946 where health care was provided for the employed population and their dependents through social security and sickness funds, financed by compulsory contributions from both employees and employers. With the Portuguese revolution in 1974, a process of health services restructuring began, culminating in 1979 in the establishment of the National Health Service (NHS) (6). This tax-financed system, guaranteed "universal, general and tendency free" health system, through a state funding budget and it included a number of different health services (7).

Following the creation of the NHS, Portuguese health policy went through several stages from the development of an alternative to the public service (early 1980s), to the promotion of market mechanisms (mid-1990s). It was only in 1990 that the Basic Law for Health was passed in Portugal, and three years later the Portuguese NHS statute came out. Both were to play a pivotal role in this critical new healthcare strategy.

While the Ministry of Health was responsible for developing health policy as well as regulating the NHS, management started at the regional level, by the regional health administrations (RHAs) (8) (Figure 1).



Source: Authors' own compilation.
Note: The Health Regulatory Agency does not include pharmacies, which is reflected in the figure, placed outside the blue box.

Figure 3.1 Chart of the Portuguese national health system
In Simões JA, Augusto GF, Fronteira I, Hernández-Quevedo C. Portugal: Health System review. Health Systems in Transition, 2017;19(2):1-184

In each of the five RHAs, there is a health administration board accountable to the Ministry of Health and responsible for strategic management of population health through the development of health directives and protocols, supervision of hospitals and healthcare services, management of the NHS primary care centres, and implementation of national health policy objectives. RHAs are also responsible for contracting services with hospitals and private sector providers for NHS patients (8).

The Azores and Madeira, as autonomous regions, have broad powers for their own health care planning and management (7). Through the years, there was overall improvement in health indicators, and the country progressively converged with the average health figures for Europe.

By the beginning of the twenty-first century, the NHS became a mixed system, based on the interaction between the public and the private sectors, integrating primary, secondary and long-term care. Reforms were enacted and aimed to combine the universal coverage provided

by the NHS and the promotion of efficiency. (8). Although the NHS incorporated most of the health facilities operating in Portugal, private provision has always been available namely in clinics, laboratory tests, imaging, renal dialysis, rehabilitation and pharmaceutical products.

Currently, the Portuguese health system is characterized by three co-existing and overlapping systems (9):

- the **universal NHS**, offering universal coverage;
- the **health subsystems** with special health insurance schemes for particular professions or sectors (e.g. civil servants, employees at banks and insurance companies, public services workers), providing care to 25% of the population. Health care is provided either directly or by contract with private or public providers, in some cases by both;
- the **private voluntary health insurance** (VHI), introduced in 1978 and reaching now 10% of the Portuguese population (with 7% having mutual funds). There are also **religious charities** that act as independent non-profit-making institutions focusing, in the last years, mainly on long-term care.

Since 2003, the majority of NHS hospitals have been given similar status to those of a public-interest company (in what may be termed "autonomous public hospitals", whereby the government retains ultimate ownership but gives some autonomy to hospital management – Hospitals EPE). This represents an attempt to introduce a more corporate structure into hospital management, with the expected effects on efficiency and cost-containment (8).

Current political agenda in Portuguese healthcare, combine the expansion and re-orientation of the policies launched by preceding governments (hospitals considered as public enterprises) with a new approach in terms of the role of the public, as well as the private and social sectors. The Portuguese health system is now viewed as a network of healthcare services between different sectors, were the citizens must choose between different options according to their needs and their preferences (Figure 2) (8).

	Legislation	Planning	Licensing/accreditation	Pricing/Tariff setting	Quality assurance	Purchasing/Financing
Public health services	Ministry of Health	Ministry of Health	Ministry of Health and Health Regulatory Agency	Ministry of Health	Ministry of Health and Health Regulatory Agency	Ministry of Health
Ambulatory care (primary and secondary care)	Ministry of Health	Ministry of Health (for the public sector)	Ministry of Health (for the public sector); Health Regulatory Agency (for the private sector)	Ministry of Health (for the public sector)	Ministry of Health and Health Regulatory Agency	Ministry of Health (for the public sector), patients
Inpatient care	Ministry of Health	Ministry of Health (for the public sector)	Ministry of Health (for the public sector); Health Regulatory Agency (for the private sector)	Ministry of Health (for the public sector)	Ministry of Health and Health Regulatory Agency	Ministry of Health (for the public sector), patients
Dental care	Ministry of Health	None	Health Regulatory Agency	Depends on the provider	Health Regulatory Agency and Portuguese Dental Association	Patients, VHI, health subsystems
Pharmaceuticals (ambulatory)	Ministry of Health	Legislation defines pharmacies' location	INFARMED	INFARMED	INFARMED	Patients, VHI, health subsystems
Long-term care	Ministry of Health; Ministry of Labour, Solidarity and Social Security	Ministry of Health; Ministry of Labour, Solidarity and Social Security	Ministry of Health; Ministry of Labour, Solidarity and Social Security	Ministry of Health; Ministry of Labour, Solidarity and Social Security	Ministry of Health; Ministry of Labour, Solidarity and Social Security	Ministry of Health; Ministry of Labour, Solidarity and Social Security; patients
University education of personnel	Ministry of Science, Technology and Higher Education	Public and private universities	Ministry of Science, Technology and Higher Education	Ministry of Science, Technology and Higher Education; universities	Ministry of Science, Technology and Higher Education; universities	Ministry of Science, Technology and Higher Education; students (fees)

Source: Authors' compilation.
Notes: INFARMED: National Authority on Drugs and Health Products; VHI: voluntary health insurance.

Figure 3.2 Responsibilities in the Portuguese national healthcare system by sector
In Simões JA, Augusto GF, Fronteira I, Hernández-Quevedo C. Portugal: Health System review. Health Systems in Transition, 2017;19(2):1-184

Funding

The national health service is predominantly funded through general taxation. The contributions of employers (including the state) and of employees represent the main source of finance of health subsystems. Furthermore, direct payments by patients and voluntary health insurance premiums represent a large part of the financing. More than 95% of NHS funding comes out of the state budget, with the rest made up of revenue from patient co-payments, subsystems and insurance. Hospital budgets absorb 53% of NHS funding, while primary healthcare facilities are financed by the regional health administrations and have no financial or administrative autonomy (6; 10).

The Ministry of Finance fixes the annual budget of the national health service based on historical spending and plans laid down by the Ministry of Health. The Central Administration of Health System (CAHS), which is the department responsible for financial management within the Ministry of Health, prepares estimates detailing the resources required to support planned activities. The estimate of total expenditure for the current year is adjusted by the expected increase in the level of consumption and salary levels. The Ministry of Finance, based on macroeconomic considerations, ultimately determines the global budget for health (8). Hospital budgets are defined and allocated at the central level, while a part of the budget is allocated to each RHA for the provision of primary health care to a geographically defined population. In order to provide an adjustment for health care needs, the capitation component is adjusted by demography (age and gender) and also by a disease burden index, according to the regional prevalence of selected health problems, namely four chronic conditions: hypertension, diabetes, stress and arthritis (8; 10).

A philosophy of paying hospitals for effective “production” of acts and services rendered to users has been introduced, as opposed to the former scheme of provisional twelfths of the State budget based on previous budget histories. (7).

Primary health care services

Primary health care has been focusing on transforming traditional health centres into functional network units. Self-managed family health units with performance related pay and incentives for better performance in health outcomes; community health care units; other health specialities support units and public health units have been developed in order to create more autonomous and multidisciplinary teams in primary care (9).

The aim of this patient centralized approach, is the expansion and improvement of primary health care network with subsequent improvement of quality and efficiency of the first line healthcare in NHS. This has been developed through a culture of clinical and health governance, modernization and reframing the health care facilities and update the information systems (11).

The primary health services in the public sector are principally carried out by general practitioners and family doctors who work in the primary healthcare centres. There is no direct access to secondary health services, with general practitioners acting as gatekeepers. Secondary and tertiary care are ensured by the hospitals, even if certain health centres offer specialist ambulatory care (7).

Hospital Care

Since 2010 a new hospital management law was passed for all hospitals that called for heightened management responsibility, upgraded efficiency, effective assessment of professionals and introduction of financial incentives. As a result, more than 1/3 of the public hospitals were corporatized and designated Public Corporate Entities (PCEs). This new legal framework allows for greater administrative autonomy and financial accountability in hospital management, while permitting greater leeway in purchasing equipment and materials and in hiring employees (12).

In 2017, in Portugal, there were 225 hospitals and 34.953 beds for inpatients. Of the hospitals, 111 were public hospitals responsible for 68.8% of the total number of beds and 114 were private hospitals with the remaining beds (13).

PCE hospital employees are currently covered by in individual work contracts. Other, non-corporatized public hospitals (the Public Administrative Sector hospitals, or PAS hospitals) are expected to follow suit, improving their overall performance by following the benchmarks set by the PCEs. Modern partnership models have also been adopted, in which public-private partnerships (PPPs) of the Private Finance Initiative type have been set up. This involves the construction, financing and operation of new public NHS hospitals by private entities (7; 12). Research has shown that PPP hospitals are generally efficient, in particular the hospitals of Braga and Cascais, which presented outstanding positive results. However, it was not possible to identify statistically significant differences between the results of the PPP and the non PPP subgroups (9).

Hospitals are paid on global budgets based on diagnosis-related groups, with the possibility to reallocate resources across cost-categories. In addition to the transfers from the government, hospitals generate their own revenue, through flat rate user charges for outpatient and diagnostic services, emergency department admissions or special services (such as specific nursing care). A new system of incentives for hospital performance was created in 2017, which values comparisons and positive competition among institutions, identifying the differences in care performance and efficiency that now occurs in hospitals with similar characteristics, providing operational levers to encourage improved performance. This new mechanism considers a set of objectives that are used to make comparisons of performance among the hospitals of the NHS, organized in benchmarking groups, focusing on the areas of access, quality and efficiency. Hospitals are reimbursed for the comprehensive treatment provided to patients for several chronic diseases: HIV infection, multiple sclerosis, pulmonary hypertension, different lysosomal storage diseases, familial amyloid polyneuropathy and selected oncological diseases (i.e. breast cancer, cervical cancer, colo-rectal cancer). The price for the comprehensive treatment was based on the clinical guidelines for each disease and it includes medicines, consultation, medical tests, etc. (12).

Long-term Care

A national network of continuing care, especially aimed at the elderly and the chronically ill, including end-of-life care, and people undergoing lengthy recoveries was also created late in 2006. Given the populations' need for public sector involvement in long-term care, a network of long-term care providers (National Network of Long-Term Care) was set up mainly through inpatient admission in private institutions (largely non-profit-making), but also as outpatients with the help of home-teams (7; 12; 13). Their multidisciplinary approach through health, social and familiar interventions aims for the full recovery of the patient, promoting functional independence and, as so, improving their quality of life (16).

This network focuses mainly in 3 areas:

- **Inpatient units** where patients stay for up to 1 month, up to 3 months or 6 months or longer according to their progress in recovery and their care needs;
- **Outpatients** clinics mainly for rehabilitation;
- **Home-teams** that provide care in the community and patients homes.

The financial responsibility of the public sector is shared between the Ministry of Health and the Ministry of Labour, Solidarity and Social Security (8). The patient either pays an amount

according to their own incomes (longer stays at the units) or benefits of the care free of charge (12; 13).

Information and communications technology

The CAHS is the service within the Portuguese Ministry of Health responsible, in a centralized manner, for the study, guidance, assessment and implementation of ICT. Established in 2007, one of the main goals of CAHS was to develop an information system and the infrastructure needed to support it. Besides producing several ICT software for registration and analysis of health units, CAHS also made available to all citizens a fair amount of information on hospitals, primary care centres and other Portuguese NHS institutions and projects (8).

The ICT systems in Portugal have started to upload data regarding patients' health since the 90's and a great effort has been made to implement a national ICT system, operable in every health facility and in the patients' personal computer. The main objective is to use ICT to place the citizen at the centre of the health system, while increasing the quality of services provided, increasing the efficiency of the system and reducing costs (12; 13).

ICT in Portugal is organized in three main bundles (14; 15):

- **E-health** aims to connect health professionals to the patients, through the share of scientific and personal information. Through these networks, Portugal was able to improve the backbone communication infrastructure of the health sector and improve information exchange between health service providers. Also, from the patient point of view, applications based on internet and mobile services assist on continuous monitoring of some chronic illnesses (diabetes, high blood pressure, obesity, drug dependency), support medication and treatment follow-up, and support the patient's family.
- **IT Services** are based on a network of multiple central and local records, managed by Shared Services of Ministry of Health (SSMH). One of the main networks is the Electronic Health Record (EHR), that allows any clinician access to clinical information, regardless of time or place of the health professional and the patient. This national network is available in almost every public health facility, with one individual file *per* person in Portugal.
- The **social media** have the role of spreading citizenship through shared information and health education.

Many actions have been taken at the level of leadership and governance; strategy and investment; services and applications; infrastructure; interoperability; legislation, policies and compliance and human resources (15). Some examples are:

- ENESIS 2020 - National Strategy for the Health Information Ecosystem;
- PENTS - National Strategic Plan for Telehealth (document in final discussion);
- SIMPLEX, particularly Simplex + Health - National Program under Agency for Administrative Modernisation (AMA) – a national program of modernization of the State, in the area of health;
- RIS - Health Informatics' Networks (Infrastructure);
- MEM - Medical Electronic Prescription (Dematerialization of prescription and dispensation);
- Electronical Health Record (EHR) – including access by citizens; Referral (system for referral between health care facilities); Live (platform for teleconsultations in real time);
- SClínico - record of medical and nursing notes and access to patients' data;
- "Exams without paper" (digital delivery of diagnostic results across health care facilities and directly to the patient);
- SICO - Digital Death Certificate;
- eBoletim - Digital Vaccine Record;
- Involvement with European structures and initiatives.

Regarding the specific systems available in Portugal, the EHR guards the information of every patient, from medical notes, laboratory results, imaging reports, emergency department entries, etc. It is directly linked to several networks that integrate each aspect of a patients file, allowing the hospital clinician or the General Practitioner (GP) to easily access the information in the different sites through one single app. Another feature of this system, is the opportunity to read the patients Advanced Care Directive or death certificate. The online Citizen Area allows people to access their electronic health records, book an appointment with a GP and check their vaccination card. There are now over 2,250,000 users, a number which on average increases by 300 users a day (5).

Another useful ICT system, is SClínico. This allows the input of medical and nursing notes for inpatients admitted in the wards ant outpatients attending consults, day hospital or emergency department. It also allows prescription of hospital and pharmacy medications, access to RSE records, orders for biologic samples or imaging tests, referrals to other

hospitals or specialities inside the same hospital and other more specific features. SClínico is the basis of every doctors' online network at the public setting. E-prescriptions through PEM, has part of this network, have become a particularly popular service. Instead of patients receiving a paper prescription, they get it over text or email. Portugal is also taking this popular service one step further by becoming the first in the EU to provide the full cross-border services of patient summary and e-prescriptions by the end of November 2020 (5).

Palliative Care has a specific platform called GestCare PICC, that allows the referral to Palliative Care facilities inside the public network and a record of those specific patients' healthcare information, from appointment schedules, medical notes to prescription or laboratory results. This ICT system is of exclusive use for the National Network of Long-Term Care, but it is possible to access the EHR platforms through a plug-in (17).

Another important Portuguese system is the Hospital Information Integrated System - SONHO. This platform is used for the management of admissions and discharges, characterization of the patients' hospital episode (from consults, imaging exams, outpatient surgery, etc.), record of paid and unpaid tax fees and assignment of the disease international coding, for later financial accounting of the costs during ones stay in the hospital. The final common goal is to improve hospital management by increasing productivity. It also guarantees the correct record of patients' inflow in a hospital, sharing of information between hospitals and different systems and comparison of hospital admissions (18).

In regards to the services used by the patients, NHS has a contact centre which provides an array of clinical and administrative services to the population. This includes teletriage, telecare for the elderly, health care information, referrals, point of care tests for Hepatitis C virus and Hepatitis B virus in pharmacies or at home. A lot of these services have also been made available online with over 1.87 million users have already used the website. Additionally, there is an app, MySNS Carteira, offered where users can gather important personal information about their healthcare such as vaccine cards, access data to the NHS service, allergy registration and e-prescriptions. The app can also create reminders on smartphone calendars reminding people when to take medication. Since it was launched in 2016, it has already been downloaded 460,000 times and proving useful to many citizens (5).

Many other apps are available and most of them can be accessed through direct links or pop-ups in the previously described platforms. Nursing staff, laboratory or imaging technicians,

medical aids and other health professionals have specific apps to upload information that can afterwards be viewed on RSE or SClínico by the medical team.

Palliative Care in Portugal

The WHO estimates that over 40 million people need palliative care per year, around the world and has already recognized the efficiency and cost-effectiveness of Palliative Care services. So, the development of specific models, fully engaged in NHS and as a continuum in the individual care, is considered an ethical responsibility for every state (19).

For long, Palliative Care has been considered an essential element for any quality NHS and should be part of any care to people with chronic and/or progressive disabilities, no matter the age ou address. A national network in Palliative Care, allows the reduction of the patients and their families burden, reduces the number of days one stays in the hospital and the readmissions, decreases therapeutic frivolity, lowers admission in emergency departments and intensive care, etc., and thereafter cuts down health related costs (20).

The movement around Palliative Care in Portugal dates back to the 1990's, when several teams of Palliative Care were created inside the hospitals providing support to terminally ill patients admitted in the wards. The first university masters in Palliative Care in Portugal arises in 2002 after post-graduate degrees becoming popular since 2000. Two years later, the first National Program for Palliative Care is launched and then renewed in 2010 (21). In 2012, the XXI Constitutional Government of Portugal determined in their health program the need to improve healthcare quality and reinforce the power of the citizen in the NHS through easy and quick access to the health system and personalized human contact of the services. In that year, the Fundamental Law for Palliative Care (22) was established in order to create and put in practice the National Network of Palliative Care via the creation of a National Palliative Care Commission, responsible for designing biennial strategic plans for the development of Palliative Care in Portugal. The aim was for Palliative care to reach the three levels of care in Portugal - Primary Care, Hospital Care and Residential care (23; 24).

According to the report on the 2017-2018 Strategic Plan for the Development of Palliative Care (21), between 109.586 people died in the year 2017 in Portugal. By applying Murtagh and Higginson formula, between 75.614 and 89.861 people (69% to 82%, respectively) needed Palliative Care in Portugal in that same year. Regarding the paediatric group, a total

of 406 children diet in 2017 and over 7900 children had complex chronic diseases and were in need of Palliative Care (21; 25; 26).

Table 1 shows the most update setting of Palliative Care resources in Portugal and the estimate needs by the end of 2020, according to the Strategic Plan for the Development of Palliative Care (SPDPC) 2019-2020 (25).

	HOSPITAL BEDS FOR PALLIATIVE CARE		HOME TEAMS	HOSPITAL LIAISON TEAMS
WHAT WE HAD BY THE END OF 2018	381		21	43
	213 (public hospitals)	168 (hospices)		
ESTIMATE NEEDS FOR 2020	392 to 491		54	45

Table 3.1 Reality and Needs for Portugal in Palliative Care

Besides the estimates for the needs in Palliative Care, the SPDPC also acknowledges the need for training and education in this area, suggesting a minimum number of 810 hours working in Palliative Care for the coordinator of the team and minimum of 70 to 140 hours for any other team member, alongside advanced theoretic training in Palliative Care (23; 24).

The Portuguese goal for biennial 2018-2020 is that “every person, with a severe chronic or incurable disease, in an advanced and progressive state, have access to quality Palliative Care, regardless of their age, diagnosis, residency or socio-economic state, from the diagnosis until death”. In order to fulfil this statement, Portugal is building an integrated model for Palliative Care, which includes specialized teams and a Palliative Care approach. The latter, is defined as an essential skill that should be universal in every health related care and profession, allowing for a specific, organized and structured approach without being specialized Palliative Care. This concept is advisable for patients with moderate to low complexity diseases, and relies on the healthcare professionals’ ability to identify the need for Palliative Care and start basic measures to the patient and their family, while waiting for a referral or a response to the referral (21; 23; 24).

On the other hand, specialized Palliative Care is responsible for the care of complex palliative patients, education of others and research. This line of care involves multidisciplinary teams that ensure follow-up to the patient and family with high degrees of complexity; liaison for

other health professionals; partnerships with universities and research centres for the development of education, teaching and investigation in this field. Through this, Palliative Care health professionals provide the basic training to other health professionals, from young doctors to GP's, nurses or psychologists, mainly to provide them with the necessary resources to precociously identify the patients that may benefit from Palliative Care and even provide initial care in chronic and/or progressive illnesses. These teams include community support teams, hospital liaison support and hospices (21-24).

When a patient needs admission at Palliative Care Unit, a first evaluation by a Palliative Care doctor and nurse is made, with definition of goals of care and needs for the patient and family. There is also a social evaluation and a formal Edmonton Symptom Assessment Scale appraisal. The admission criteria for these units are strict and usually a patient should only stay for 30 days or less. They must fulfill **all** the following criteria (26):

- Presence of an incurable advanced and progressive illness and, in case of cancer patients, they can't be on chemotherapy treatment, immunotherapy or any other systemic treatment;
- Need for active management, from physical symptoms, psychological, social or spiritual;
- Need for permanent nursing care;
- Need for daily, but not permanent, medical care;
- No need for regular appointments by other specialities during their stay at the hospice.

Rarely there can be an admission for carer respite, but these aren't common in Portugal mainly because of the lack of beds available (26).

Information and communications technology and Palliative Care

To ensure the transferring of patients according to ones' needs, it is essential that the connection and network from hospitals or family practices to Palliative Care teams are easy and quick. This is accomplished through ICT systems and/or direct contact via telephone or in person. The main ICT system providers remain EHR and SClínico, as mentioned before. When a patient is in need of an admission to Long-care facilities, his data are inserted into GestCare and becomes part of the waiting list.

Referral of patients to Palliative Care varies according to the hospital or primary care facility. If a patient is at home and the GP or other doctor identifies the need for Palliative Care, a

referral is put in place through SClínico application, going through directly to the Palliative Care team of the correspondent hospital. After triage, the Palliative Care coordinator prioritizes requests and determines if and when the patient needs to be observed in clinics or at home. In an inpatient, the process is similar but the response is usually faster, between 24 hours to 5 days. If an urgent situation arises, the contact is made via telephone and an urgent computer referral is made (27).

Every health professional on both sides of these chain, are required to register their assessment of the patient, the time of evaluation, the plan for the individual and his family and the next appointment. This way, through SClínico the referring doctors are able to follow the developments of the case and help with lab works or prescriptions when in need.

Palliative Care is mainly paperless in Portugal, relying on the several online platforms available.

Future plans

The Carteira application is hoping to add new features in the future, including teleconsultations. This update will enable video calls within the app for healthcare professionals to contact and engage other healthcare professionals in other departments or practices. These teleconsultations have already been shown to work well between healthcare providers and streamlines information between services. Some uses include support video calls, sharing of clinical images and lab tests results (5).

Section Summary

Although being today at the forefront of digital health, Portugal still needs to strengthen the existence of a common vision, shared by the various actors, at the national level. It needs to encourage coordination and cooperation between the various stakeholders in the development and adoption of e-health (global digital health index). Investment in the current apps is essential for their future. Some have become obsolete, overpowering the systems and with a few extra clicks required. Portuguese developers still need to improve a few of these platforms and specially promote digital health literacy for the patients and the health professionals (5; 8).

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Appendices

Appendix1 – Sample search strategy

Database(s): **Ovid MEDLINE(R) and Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Daily and Versions(R)**
Search Strategy:

#	Searches	Results	Annotations
1	general practice/ or family practice/	74700	
2	general practitioners/ or physicians, family/	23973	
3	Primary Health Care/	76500	
4	(Primary care or Primary healthcare or primary health care or General practice* or General medicine or General practitioner* or Family practice* or Family medicine or Family practitioner* or Family physician*).tw,kf.	228316	
5	or/1-4	278558	General practice
6	Mobile applications/ or Telephone/ or cell phones/ or cellular phone/ or smartphone/ or text messaging/ or wireless technology/ or video games/ or computers, handheld/	40118	Mobile apps - ipads, phones ...
7	(mobile application* or smartphone* or iphone or messaging or text messag* or texting or interactive voice response or app or apps or ICT application* or mobile device* or wireless device* or wireless technolog* or ipad* or tablet comput* or tablet device* or instant messag* or short messag* or SMS* or MMS or mobile web or whatsapp).tw,kf.	60346	
8	or/6-7	88517	
9	social media/ or webcasts as topic/	7716	social media apps
10	(webcast* or podcast* or social media* or social networking or twitter or facebook* or instagram* or Youtube* or video clip* or audio clip* or games or gaming or videogam* or wiki*).tw,kf.	38226	
11	or/9-10	40153	

12	telemedicine/ or telenursing/ or remote consultation/ or telemetry/ or remote sensing technology/ or monitoring, ambulatory/ or videoconferencing/	44735	Telehealth
13	(Telemedic* or telehospice* or telehealth* or telecare* or telenursing or telehome* or telemonitor* or telerehab* or telemetr* or teleconferenc* or teleconsult* or televideo* or remote consult* or (remote adj2 monitor*) or virtual hospital* or video conferen* or videoconferenc* or assistive technolog* or virtual monitor* or virtual visit* or eVisit* or (tele adj (medic* or hospice* or health* or care* or nursing or home* or monitor* or rehab* or metr* or conferenc* or consult* or video*))).tw,kf.	35149	
14	or/12-13	61978	
15	Electronic health records/ or Medical Records Systems, Computerized/ or medical informatics/ or medical informatics applications/ or biomedical technology/ or health information exchange/ or health information systems/	56986	EHRs
16	(Electronic health record* or EHR? or electronic medical record* or electronic healthcare record* or personal health record* or patient portal* or electronic health registr* or eRegistr* or e-registr* or eRegister* or eReferral* or electronic referral* or electronic consultation* or eprescri* or e-prescri* or health informatic* or medical informatic* or digital form or electronic form).tw,kf.	40930	
17	or/15-16	80404	
18	(Wearable? or fashionable tech* or fashion tech* or fashion electronics or smart electronic device* or smartwatch* or smart watch* or ((health or activi* or fit* or step* or move* or moving or motion* or calori* or kilojoule* or sleep or wireless or personal) adj3 (sensor* or track* or monitor* or count*))).tw,kf.	90799	wearables
19	(accelerometer* or actigraph* or actimetry sensor* or fitbit* or pedometer* or "Withings Pulse" or mi band).tw,kf.	21203	
20	or/18-19	106798	
21	(e-health* or ehealth* or electronic health* or e-technolog* or etechnolog* or e-consult* or digital health* or digital technolog* or digital innovation* or digital application* or digital therapeutic* or mobile health* or mhealth* or m-health* or mobile technolog* or health information technolog* or healthcare information technolog* or health care information technolog* or health care IT or healthcare IT	43836	

	or "information and communication technolog*" or e-support* or uhealth* or u-health* or ubiquitous health* or augmented reality or home monitoring or connected health*).tw,kf.		
22	Virtual Reality/ or virtual realit*.tw,kf.	10357	
23	(smart home* or smarthome* or "internet of things").tw,kf.	2515	
24	Video recording/ or audiovisual aids/ or multimedia/ or (video* or audio* or multimedia).tw,kf.	190476	
25	Telecommunications/ or computers/ or computer communication networks/ or computers, handheld/ or microcomputers/ or Internet/ or software/ or computer systems/	247801	
26	(online or on-line or mobile or digital* or digiti* or electronic* or computer* or software or internet* or web or website* or technolog* or cyber* or interactiv* or telecommunicat* or tele-communicat*).ti.	340967	
27	or/6-26	951120	
28	5 and 27	24771	
29	palliative care/ or terminal care/ or hospice care/ or "Hospice and Palliative Care Nursing"/ or Palliative Medicine/ or hospices/ or terminally ill/ or exp advance care planning/ or bereavement/	93608	Palliative care
30	(palliative or terminal care or terminally ill or "end of life" or hospice* or bereave* or advanced care plan* or advance care plan* or advance directive* or living will*).tw,kf.	97962	
31	(dying or death).ti,kf.	149251	
32	((life limit* or endstage* or end stage* or advanc* or progressive or non-curative* or incurabl* or terminal or late stage) adj1 (illness* or disease* or condition* or malignan* or heart failure or cancer* or organ failure or kidney failure or chronic kidney or renal failure or chronic renal or liver failure or chronic liver or hepatic failure or respiratory or neurodegenerative or neuro-degenerative or chronic obstructive pulmonary disease or COPD or dementia* or alzheimer* or motor neurone or MND or multiple sclerosis or amyotrophic lateral sclerosis or ALS or parkinson*)).tw,kf.	105246	
33	or/29-32	361756	

34	28 and 33	392	
35	exp computing methodologies/ or exp medical informatics/ or information management/ or data collection/ or common data elements/ or data accuracy/ or data aggregation/ or datasets as topic/ or forms as topic/ or records/ or data management/ or health information management/ or health information exchange/ or "information storage and retrieval"/ or information technology/	1327663	Clinical information systems
36	(clinical information adj3 system*).tw,kf.	1765	
37	clinical decision support.tw,kf.	4914	
38	35 or 36 or 37	1329866	
39	5 and 33 and 38	324	