This is a repository copy of *A survey of mobile phone use in the provision of palliative care services in the African Region and priorities for future development*.

White Rose Research Online URL for this paper:
http://eprints.whiterose.ac.uk/129687/

Version: Accepted Version

1 **A survey of mobile phone use in the provision of palliative care services in**

2 **the African Region and priorities for future development**

3

4 **Matthew J Allsop***

5 m.j.allsop@leeds.ac.uk; Academic Unit of Palliative Care, Leeds Institute of Health Sciences,

6 University of Leeds, Leeds, UK

7 **Eve Namisango**

8 eve.namisango@africanpalliativecare.org; African Palliative Care Association, Kampala, Uganda;

9 Department of Palliative Care, Policy & Rehabilitation, Cicely Saunders Institute, King's College

10 London, UK

11 **Richard A Powell**

12 richard2powell@yahoo.co.uk; MWAPO Health Development Group, Nairobi, Kenya

13

14 *=corresponding author: Matthew J Allsop. m.j.allsop@leeds.ac.uk

15 Address: Academic Unit of Palliative Care, Leeds Institute of Health Sciences, University of Leeds,

16 Worsley Building, Clarendon Way, Leeds, LS2 9NL

17

18 The published version of this manuscript is available from the Journal of Telemedicine and Telecare

19 website: http://journals.sagepub.com/home/jtt

20

1   **Abstract**

2   **Introduction**

3   Palliative care (PC) services in the African Region need to adapt to manage rising numbers of

4   patients with cancer or other life-limiting conditions. Mobile phone use in healthcare delivery

5   (mHealth) is at an early stage of development for PC, but may provide new approaches to supporting

6   patients in the African Region, particularly those with non-communicable diseases.

7   **Methods**

8   We conducted an online survey with 51 palliative care providers across 21 countries in the African

9   Region to identify: i) current mHealth use in palliative care service delivery; ii) potential barriers to

10   mHealth use, and; iii) provider priorities for research development.

11   **Results**

12   mHealth approaches were reported across 71.4% of services in which respondents were based.

13   Barriers to mHealth research include patients not having access to phones, mobile network access,

14   and limited access to expertise and hardware required for mHealth. Research priorities were

15   identified which included exploring ways of incorporating mHealth into patient care and ensuring

16   access and relevance of mHealth for patients and health professionals.

17   **Discussion**

18   mHealth approaches are present across PC services in the African Region, but so too are barriers to

19   their use. Further work is required to explore how existing mHealth activities might be further

20   developed and aligned with priority areas for PC development. Crucially, user engagement that

21   seeks to understand the preferences and priorities of patients with PC needs, their caregivers, and

22   those involved in the provision of PC should remain central to these efforts.

23   **Keywords:** non-communicable diseases; palliative care; Africa; technology; mHealth

1   **Introduction**

2   Palliative care (PC) —the prevention and relief of physical, emotional, social, or spiritual suffering

3   associated with any chronic or life-threatening illness, beginning from the time of diagnosis—is a

4   fundamental component of basic and essential health services[1]. Across the African Region, PC

5   development is at an early stage.[2] For example, in sub-Saharan Africa, PC is present in 24 of 48

6   countries, up from only five in 2004[3]. While provision of PC is increasing across the African Region,

7   still less than 5% of people who need it can access it.[4] Efforts to expand PC provision are underway,

8   but coverage remains woefully inadequate[5]. Historically, PC in the African Region has predominantly

9   focused on HIV/AIDS, partly due to donor-driven funding priorities[6]. However, recent international

10   and regional political declarations constitute a new global non-communicable disease (NCD) agenda[6].

11   This is in response to rising NCD rates; new cancer cases, for example, are projected to nearly double

12   from 645,000 in 2012 to 1.28 million by 2030[6]. This epidemiological transition requires service

13   delivery systems that are able to adapt to support patients under the chronic care service model.

14   Currently, the need for palliative care services are at risk of outstripping capacity[7] unless effective

15   strategies to promote their development are given the highest priority for implementation.[8]

16   The use of information and communication technology (ICT) in PC provision is increasing across the

17   US and Europe[9]. Benefits of ICT use in these regions include supported pain management[10] and

18   improved communication between patients and health professionals[11]. ICT approaches have also

19   been shown to lead to improvements in the scale, efficiency and accuracy of data collection[12] and

20   are acceptable to both patients [13] and health professionals [14] when used to improve cancer care

21   coordination. In the African Region, factors such as expanding penetration of mobile networks in

22   rural communities and reduced costs of mobile handsets are driving the exploration of mHealth (i.e.,

23   the practice of medicine and public health supported by mobile devices) to support delivery of

24   healthcare services.[15, 16] Mobile phones provide a means of communicating and augmenting existing

25   services to engage with patients and their families[6], enabling rapid access to clinical and social

26   support networks[17]. Consequently, mHealth approaches are viewed as promising health investments

1   in developing countries[18]. When used in this way, mHealth provides a means of communicating

2   directly with a patient or family caregiver, independent of their location, to understand their needs

3   and care preferences. Telecommunications can potentially bridge necessary health system

4   structures from rigid pyramidal to plastic networks that improve access at all levels of care[19]. In the

5   context of palliative care services in the African Region, mHealth approaches could guide the

6   exploration of new ways of communicating with, managing and coordinating patients and their

7   caregivers. For example, mHealth could facilitate the capture of much-needed evidence on symptom

8   prevalence and burden[20-23] and patient centred outcomes[24]. The ability to capture patient-level data,

9   whether using mHealth or alternative approaches, is a precondition to understanding which PC

10   components are currently effective and aligned with patient need[25]. These data can be used to

11   evaluate the effectiveness of existing services, directing where adaptation to PC services is required

12   and incorporating the voice of patients and their families in care. mHealth may also provide a means

13   of supporting PC patients with NCDs requiring longer engagement periods, providing flexibility

14   during their illness trajectory dependent on levels of assistance required[6]. For health professionals

15   too, mHealth approaches could be explored for overcoming a key challenge of PC in the African

16   Region; a lack of PC education.[26]

17   In the African Region, the proliferation of mHealth approaches has demonstrated successes with

18   chronic disease management[27], patient behaviour change and health systems strengthening[28],

19   reducing costs of patient monitoring, and improving adherence and communication[29]. However, the

20   implementation of mHealth is threatened by factors such as dependency on funding, unclear

21   healthcare system responsibilities, unreliable infrastructure and a lack of evidence on cost-

22   effectiveness.[16] Whilst this could be an opportune time to explore how evidence-based mHealth

23   interventions might form part of the evolving PC services in the African region,[30] mHealth

24   development needs to be planned, measured and evaluated. For example, existing mHealth activity

25   and the capacity of PC services in the African Region to develop mHealth approaches is not well

26   understood. A recent literature review on mHealth use in PC services in sub-Saharan Africa identified

1 early research activities[30], but highlighted that little is known about the extent of current mHealth

2 use or the way in which it is viewed by service providers. Addressing this gap in knowledge is

3 essential to guide further research activity. For this reason, this study aims to identify: i) current

4 mHealth use in palliative care service delivery in the African Region; ii) potential barriers to mHealth

5 use, and; iii) provider priorities for research development.

6

7 **Methods**

8 We adopted a mixed methods descriptive design, using an online survey in English and French,

9 conducted between May and August 2016. The survey sought to capture responses from the African

10 Region, encompassing both North Africa and sub-Saharan Africa. PC provision in North Africa, most

11 developed in Morocco and Egypt, is still in the very early stages of service development[31], mirroring

12 PC development in most countries across sub-Saharan Africa.[32] Invitations to participate in the

13 research and a link to the online survey (in the relevant language) were sent via email. Those

14 approached to complete the survey were identified using membership lists of the African Palliative

15 Care Association (APCA). APCA is a pan-African organisation that works collaboratively with both

16 providers of PC services to help expand service provision and with governments and policymakers to

17 ensure an optimum policy and regulatory framework for PC in the African Region. Their contact lists

18 contain PC providers established across the African Region and national PC associations in ten

19 countries (i.e., Cameroon, Cote D' Ivoire, Democratic Republic of the Congo, Kenya, Malawi,

20 Morocco, Senegal, South Africa, Tunisia, and Uganda). APCA sent requests for national associations

21 to distribute a link to the online questionnaire to providers that were members of their association.

22 Where national associations were absent, direct contact was made, facilitated by APCA, with PC

23 services or ministries of health where contact details were available.

24 *Questionnaire*

25 A questionnaire was developed specifically for this survey given no other instrument for assessing

26 mobile device use in health services was found, and was hosted by the Bristol Online Survey

1 (www.onlinesurveys.ac.uk) service. Respondents were asked to indicate the country in which they

2 work in PC, their professional role, and length of PC experience. They were also asked to provide

3 details on the service(s) in which they are based, including geographical region covered (i.e., urban,

4 rural, peri-urban) and types of delivery (i.e., inpatient care, outpatient care, home visits, day care).

5 Respondents were presented with the image shown in Figure 1, which was informed by the World

6 Health Organization (WHO) visual framework for mHealth innovations as health system

7 strengthening tools[33]. Four key stages of PC delivery models, typical in the Africa Region,[3] were

8 added to the top of the figure. This enabled the charting of which uses of mHealth are occurring for

9 PC provision across the advanced disease illness trajectory. A draft version of the adapted

10 framework was shared with seven PC organisations in Rwanda, Kenya and Uganda for comment.

11 Following two iterations, the framework was finalised by two authors (MA, EN). Respondents were

12 asked, for each of the thirteen applications of mobile devices outlined in Figure 1, whether they

13 were currently using mobile devices in that way. If respondents answered 'yes', they were asked to

14 define at which of the four stages of the PC pathway this was occurring, alongside providing a

15 description of how mobile devices were being used in this way. Respondents were asked to describe

16 any other uses of mobile devices with patients and health professionals not outlined in the figure.

17 The final questions focused on respondents' priorities for research on mobile device use in PC

18 services. They were asked to state their key priority for mHealth research in PC, and to outline any

19 barriers they anticipated to the development of mHealth approaches in services and to research on

20 mHealth.

1 ***Figure 1:*** *mHealth PC framework for the African Region presented during the survey. The framework*

2 *combines the WHO mHealth and ICT framework with a care pathway depicting PC provision in the*

3 *African Region*
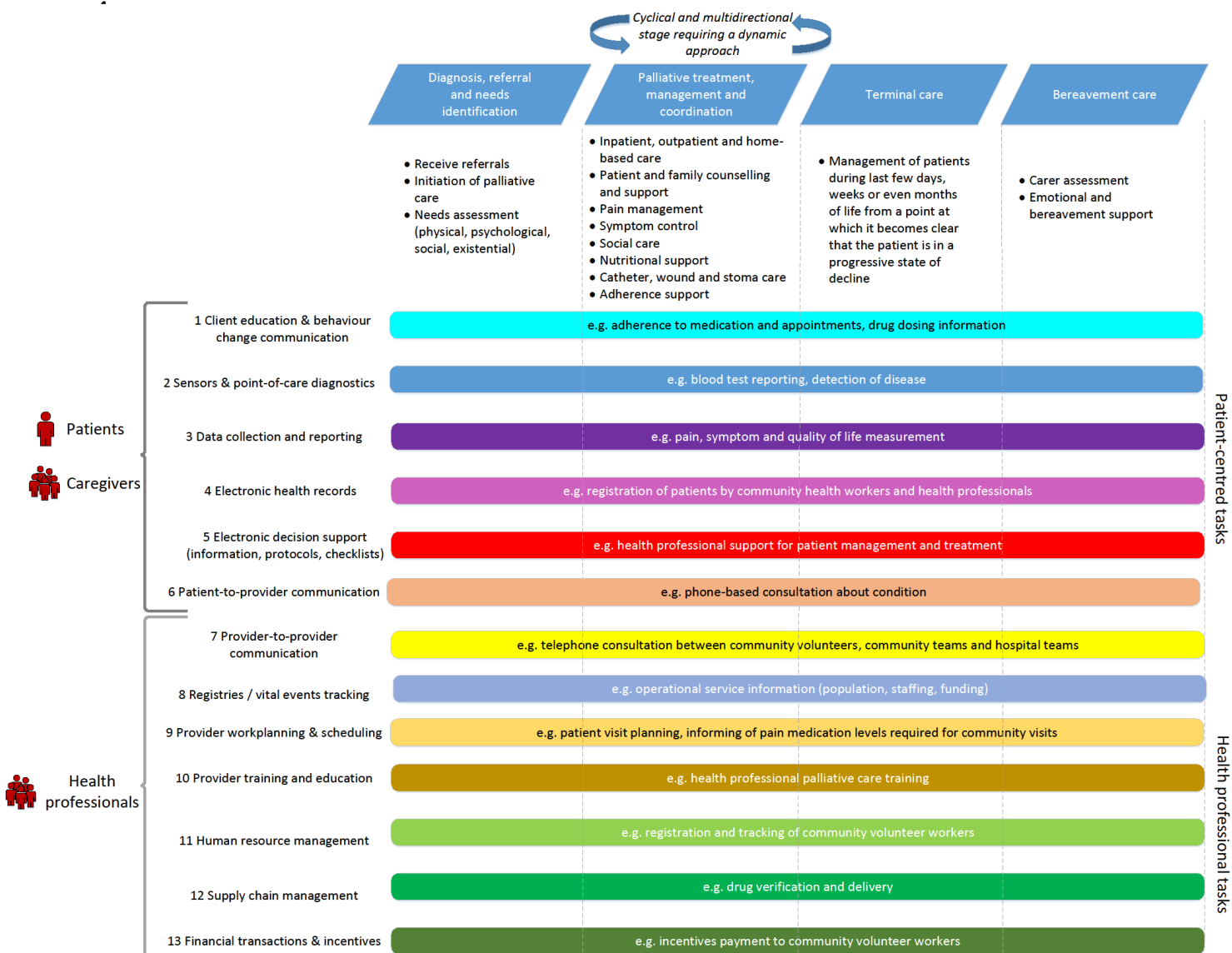
16

17 The questionnaire was piloted with 4 PC professionals across 4 countries in the African Region

18 (Cameroon, Kenya, Malawi and Uganda) prior to being distributed to all providers.

19 Sample

20 The sample consisted of PC professionals fulfilling the following criteria: working within a country in

21 the African Region where PC provision is present; contact details of the PC organisation were held or

1   could be obtained by APCA; could be contacted by email, and; had internet access to complete the

2   online questionnaire.

3   Analysis

4   Descriptive analysis was performed on responses, completed using SPSS (v.22). Findings were

5   synthesised using geographical information system (GIS) software (i.e., ArcGIS). Free text responses

6   were analysed using content analysis conducted independently by two researchers (MA, EN),

7   supported by NVivo software (v.10).

8   **Results**

9   In total, 101 PC organisations were contacted across 32 countries in the African Region, including

10   national associations in 10 countries. There were 51 responses to the questionnaire from 21

11   countries; a response rate of 50.5%. All responses were recorded via the online questionnaire

12   system. Data were collected between May and August 2016. Respondents were from services that

13   varied in staff composition, size, service provision and geographical region served. Respondents to

14   the questionnaire comprised of a number of different job roles across countries (Figure 2a). The

15   most common respondents were nurses (n = 25; 49.0%), physicians (n = 7; 13.7%), administrators (n

16   = 4; 7.8%) and clinical officers (n = 4; 7.8%).

17

1   ***Figure 2:*** *(a) Job role and (b) experience of survey respondents.*

2
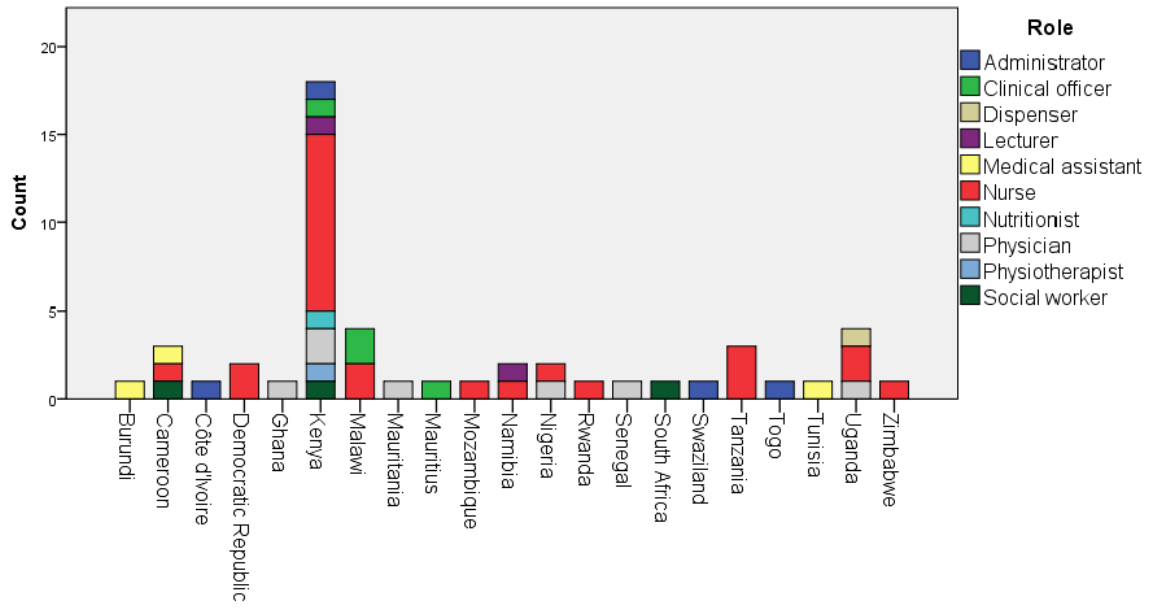
3

1   Years' experience of respondents varied (figure 3b), with most respondents (n = 39; 76.5%) having

2   between 1 – 8 years of experience in their current role. The team sizes varied from 2 – 100 (IQR = 8)

3   staff members, with years of experience working in PC services ranging from 1 – 20 years (IQR = 5)

4   (figure 2b). Three services also outlined they had 400 (Malawi), 50 (Democratic Republic of the
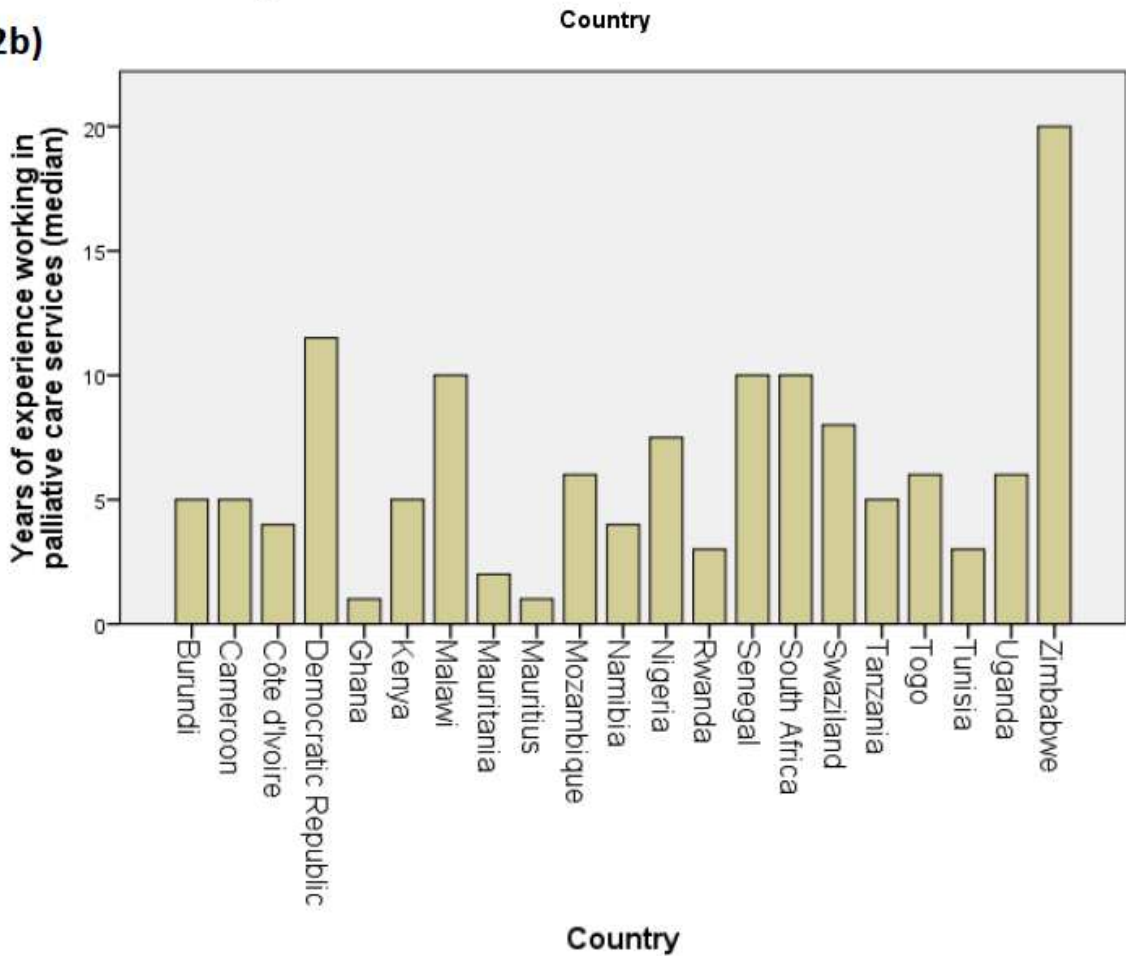
5   Congo) and 300 (Zimbabwe) volunteers involved with their services alongside clinical staff.

6   Geographical coverage of PC services were reported as urban (n = 34; 66.6%), peri-urban (n = 10;

7   19.6%) and rural settings (n = 11; 21.6%), with seven services reporting coverage across more than

8   one geographical setting. Clinical services were delivered through inpatient services (n = 29; 56.9%),

9   outpatient services (n = 36; 70.6%), day care (n = 24; 47.1%) and home visits (n = 35; 68.6%).

10   **Reported mHealth use**

11   mHealth use was reported across 15 of the 21 (71.4%) countries from which responses were

12   obtained (figure 3). The most commonly reported mHealth uses were for patient education and

13   behaviour change communication, data collection and reporting, and patient-to-provider

14   communication (as detailed in table 1). The mHealth use reported least across participants was to

15   support sensors or point-of-care diagnostics; reported by providers in 2 (9.6%) countries.

1   ***Figure 3:*** *Number of mHealth uses reported by respondents across participating countries.*
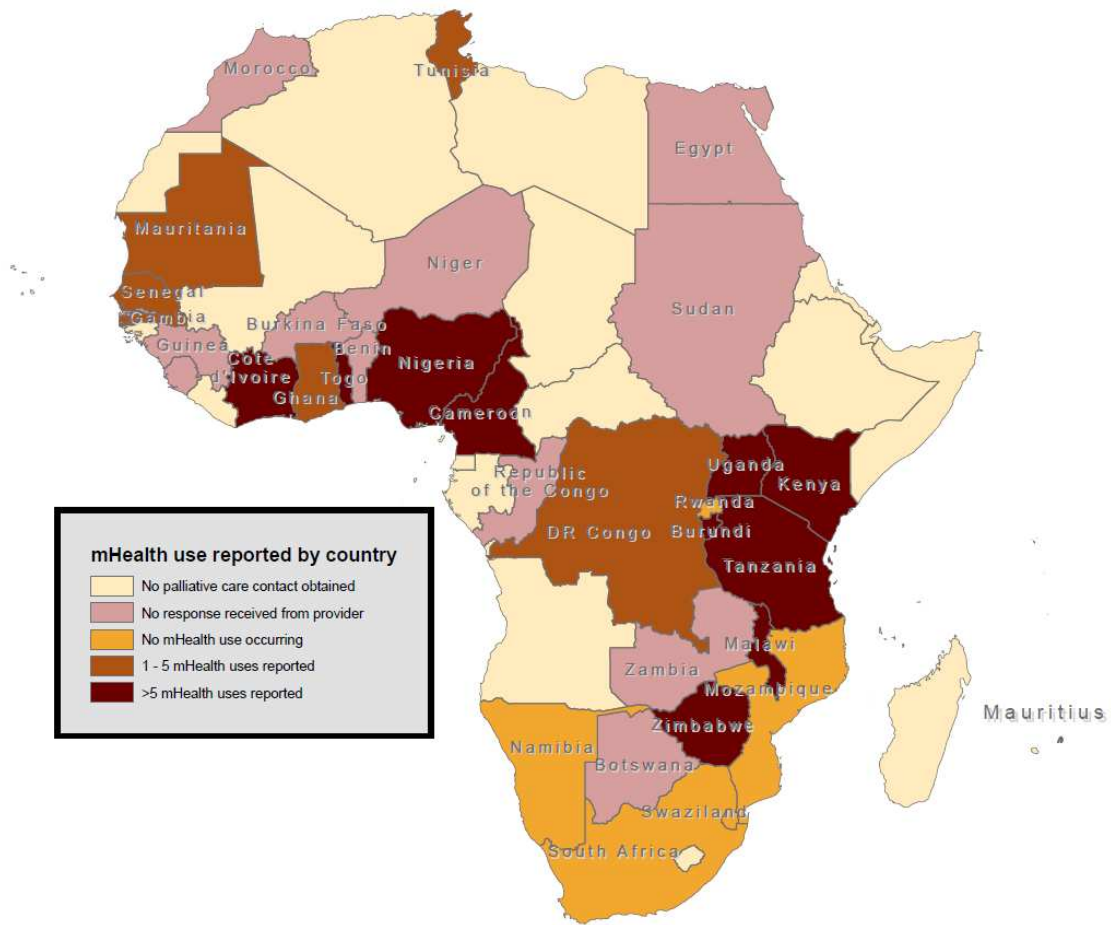
2

Country	Patient education and behaviour change communication	Stage	Sensors or point-of-care diagnostics	Stage	Data collection and reporting	Stage	Electronic health records	Stage	Electronic decision support	Stage	Patient-to-provider communication	Stage	Health professional-to-health professional communication	Stage	Support registries or vital events tracking	Stage	Work planning or scheduling	Stage	Training and education	Stage	Human resource management	Stage	Supply chain management	Stage	Financial transactions and incentives	Stage	Number of mHealth uses by country
Burundi	Yes	ABCD	No	-	Yes	B	Yes	B	Yes	B	Yes	ABCD	Yes	ABCD	Yes	B	Yes	BC	Yes	ABCD	Yes	BCD	Yes	BC	No	-	11
Cameroon	Yes	ABCD	No	-	Yes	ABCD	No	-	Yes	ABCD	Yes	ABD	Yes	ABCD	No		Yes	BC	Yes	AB	Yes	ABC	Yes	B	Yes	AB	10
Côte d'Ivoire	No	-	No	-	No	-	Yes	AB	Yes	AB	Yes	A	Yes	B	Yes	BC	Yes	AB	No	-	No	-	Yes	B	Yes	BD	8
Democratic Republic of the Congo	No	-	No	-	Yes	C	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	1
Ghana	Yes	BC	No	-	No	-	No	-	No	-	Yes	BC	Yes	ABC	No		Yes	B	No	-	No	-	No	-	Yes	B	5
Kenya	Yes	ABCD	No	-	Yes	ABC	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	B	12
Malawi	Yes	ABCD	No	-	Yes	AB	No	-	No	-	Yes	ABC	Yes	AB	Yes	B	Yes	B	Yes	B	No	-	No	-	Yes	AB	8
Mauritania	No	-	No	-	Yes	ABD	No	-	Yes	AB	Yes	ABCD	Yes	ABC	No	-	No	-	Yes	AB	No	-	No	-	No	-	5
Mauritius	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Mozambique	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Namibia	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Nigeria	Yes	AB	No	-	Yes	ABCD	No	-	Yes	ABC	Yes	ABCD	Yes	AB	No	-	Yes	B	Yes	AB	No	-	Yes	B	No	-	8
Rwanda	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Senegal	Yes	AB	No	-	Yes	AB	No	-	Yes	AB	Yes	AB	No	-	No	-	No	-	No	-	No	-	No	-	No	-	4
South Africa	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Swaziland	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	0
Tanzania	Yes	ABC	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABC	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABC	Yes	B	Yes	ABCD	13
Togo	Yes	BD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	BD	Yes	ABCD	Yes	ABCD	Yes	ABCD	Yes	ABCD	13
Tunisia	Yes	D	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	No	-	1
Uganda	Yes	ABCD	No	-	Yes	ABCD	No	-	No	-	Yes	BCD	No	BCD	Yes	ABD	Yes	ABCD	Yes	BCD	Yes	ACD	No	-	No	-	7
Zimbabwe	Yes	ABCD	No	-	Yes	B	No	-	Yes	B	No	-	No	-	No	-	Yes	BCD	No	-	Yes	B	Yes	BC	No	-	6
Number of uses of mHealth	12		2		12		5		10		12		10		7		11		9		7		8		7		
Proportion of countries	57.14%		9.52%		57.14%		23.81%		47.62%		57.14%		47.62%		33.33%		52.38%		42.86%		33.33%		38.10%		33.33%		

1   **Key for reported stage of mHealth use in palliative care pathway**: A = Diagnosis, referral and needs identification; B = Palliative treatment, management and coordination; C = Terminal care; D = Bereavement care.

2   **Table 1:** Overview of mHealth uses reported across participating countries

1   Respondents provided a range of descriptions of how mHealth was being used for all 13 mHealth

2   applications in the mHealth framework. Examples of descriptions provided by respondents are

3   outlined in Table 2.

4

5   **Research priorities for mHealth in palliative care in the African Region**

6   ***Priorities for research on mHealth***

7   Research priorities proposed by respondents were coded into 6 themes (table 3).

8

9   ***Barriers to mHealth use in palliative care services***

10 Across respondents, six barriers to developing mHealth approaches in PC were identified: i) patients

11 not having access to phones (whether through lack of money or not owning their own phone); ii)

12 mobile network access, with unreliable networks and limited internet in some countries; iii) limited

13 access to expertise and hardware required for mHealth use (e.g., limited expertise to set up and use

14 new mobile phone technology, lack of computer literacy in healthcare teams, need for electricity

15 points to charge mobile devices); iv) existing limits to the capacity of services (such as limited

16 administrative support to take on additional tasks associated with mHealth approaches); v) financial

17 and cost constraints (e.g., airtime costs for voice and text communication on mobile phones), with

18 cheaper methods of communicating, such as WhatsApp, not being available on cheaper phones, and;

19 vi) governance constraints (such as those arising from resistance to adoption or buy-in from

20 ministries of health, or institutional protocols to mHealth use).

	mHealth use	Examples of descriptions of use
Patient-centred tasks	Patient education and behaviour change communication	**Cameroon:** To take appointments or confirm appointments with patients and to follow up patients or pass urgent information to patients **Kenya:** Patients contact us via mobile phone if they have questions about medications, appointments or new symptoms, and we advise and respond to their questions
	Sensors or point-of-care diagnostics	**Togo:** Communicating about blood tests or additional medical tests
	Data collection and reporting	**Mauritania:** We have both a pain visual analogue scale and a faces scale, on the tablet computer. The patient can either point somewhere on the line or a face on the scale, the clinician then records this by ticking the relevant box. This is still at early stages and is not our routine practice **Uganda:** During treatment patients are called up to find out if their symptoms are improving on a given medication and the score of their symptom recorded
	Electronic health records	**Mauritania:** All health records within the project are electronic, with no hard copies. So it is only used internally within the project. I am not aware of any other electronic health records in the country. **Kenya:** This helps us to identify treatments clients are on even if the files are missing
	Electronic decision support	**Kenya:** For confirmation of treatment and protocols **Kenya:** Software installed on the phone to some health professionals for use to inform consultations during the continuum of care
	Patient-to-provider communication	**Kenya:** The patient or relative can call to consult, to inform that they are coming for services, to get clarification. For follow up especially if a patient is very sick to offer support to the family, just to be there but via the phone **Kenya:** Patients can self-refer to the project by phoning one of the project's mobile phone numbers (kept with the local nurses). Patients and families can use this number to seek advice or request a visit.
Health professional / process tasks	Health professional-to-health professional communication	**Kenya:** Everyone on the team has a mobile phone. We do face-to-face patient reviews as a team every day, but when questions or issues arise otherwise, we communicate by mobile phone **Malawi:** Discuss management of case over phone, facilitate referral to another provider and even source medication that patients need
	Registries or vital events tracking	**Kenya:** Palliative care unit report deaths of patients to Ministry of Health **Kenya:** Monthly reports
	Work planning or scheduling	**Côte d'Ivoire:** Call patients to schedule home visits and search for those lost to follow-up **Kenya:** Making appointments for multidisciplinary team visits
	Training and education	**Cameroon:** To encourage, give information to particular problem, give or repeat directives **Mauritania:** Online learning in the office and downloading of articles for offline educational use
	Human resource management	**Togo:** This is very important to us because who does what in the chain must be made known to all, if any change in the partner teams must know
	Supply chain management	**Kenya:** Using computer system in pharmacy to track amount of stocks remaining when dispensing medications to wards and patients **Zimbabwe:** When ordering medication
	Financial transactions and incentives	**Ghana:** Patient and caregivers are able to settle bills via mobile money payments to PC unit account **Côte d'Ivoire:** Money transfer by mobile money

1   **Table 2:** Descriptions of mHealth use categories as reported by respondents

Research priority	Overview of content from respondents
1) Explore ways of using mHealth as part of patient care (n= 12; 23.5%)	Research that explores ways of incorporating mHealth into patient care was proposed as a priority by the largest proportion of respondents. Examples of specific ways in which mHealth could be explored through research included rapid communication and tracking of information about symptoms (such as pain), outcome measurement, patient and caregiver education, extending reach of PC services to peripheral hospitals, and facilitating communication between healthcare professionals and patients (e.g., arranging follow-up appointments) and their caregivers. However, respondents also acknowledged the need to understand and assess the effectiveness of mHealth as part of patient care.
2) Ensuring access and relevance for patients and health professionals (n = 9; 17.6%)	Prioritising research that ensures mHealth approaches are appropriate for users was reported. This included the need to capture patient perspectives on mHealth approaches, understanding how to make approaches accessible (e.g., for patients with limited or no experience of using mobile phones, or those who find communication difficult), and using research to explore questions around the value, effectiveness and acceptance of mHealth approaches for patients. Alongside patient perspectives, health professional perspectives should be sought. Respondents made specific mention of the need to further understand the attitudes and motivations of health staff and volunteers for using mHealth, which can be used to inform the design of interventions and may influence whether health professionals adopt mHealth approaches.
3) Stated support for mHealth research (n = 8; 15.7%)	A proportion of respondents stated support for mHealth research without specific recommendations for topic areas (e.g. "*This research is very important and useful to improve the quality of palliative care*", "*This is a good idea and will be very helpful*"). It was highlighted that research findings could help to improve patient care and will increase evidence-based practice for PC regionally.
4) Infrastructure and security development (n = 8; 15.7%)	The need to chart existing infrastructure was highlighted by respondents. To maximise and leverage mobile technology as part of services, the reliability of mobile networks in the region needs to be known. Research also needs to address the practicalities of mHealth approaches. These include developing processes for secure exchange of data between patients and health professionals, guidance on approaches to implementing and evaluating mHealth in PC services, the costs of mHealth approaches, and the development and evaluation of training in the delivery of mHealth approaches.
5) Enhancing practice of health professionals (n = 6; 11.8%)	Respondents proposed research to enhance the way health professionals operate. Suggestions to explore included how mHealth could contribute to the collection (e.g., history taking, patient assessment) and management (e.g. automated weekly and monthly reporting) of data, and the coordination of care through increasing communication between health professionals.
6) Training and education for health professionals (n = 4; 7.8%)	Research can be used to develop and evaluate approaches to supporting training and education for PC professionals in the African Region. Respondents highlighted this could increase access to training. It was emphasised that these approaches should be explored in multiple languages to support expansion of services across the African Region (e.g., Francophone countries).

1   **Table 3:** *Priorities for research on mHealth in PC in the African Region*

2

3   ***Barriers to mHealth research in PC services across the African Region***

4   A proportion of respondents (n = 15; 29.4%) suggested there were no barriers to mHealth research

5   in their service, although barriers were identified. One participant noted there may be resistance

6   from both health professionals and patients to mHealth research, fearing it will be used to replace

7   human contact. There may also be a lack of commitment to research, with limited or no research

1   personnel and capacity to conduct research in many services (n = 12; 23.5%). The lack of

2   understanding and knowledge of how to conduct mHealth research was itself seen as a potential

3   barrier to future mHealth research activities. Respondents highlighted that a further barrier to

4   conducting mHealth research was a lack of necessary infrastructure, such as having hardware and

5   the internet available at sites (n = 14; 27.5%). For patients, too, the need to have access to a mobile

6   device and network were noted (n = 13; 25.5%). Lastly, patient literacy was referred to by

7   respondents, alongside knowledge of how to use mobile devices (n = 4; 7.8%).

1   **Discussion**

2   This study presents the first survey of mHealth activity by PC service providers across the African

3   Region. Widespread use of mobile devices has been charted across a large proportion of countries in

4   which respondents were based. Each of the common mHealth and ICT applications as identified by

5   the WHO[33] were reported. Multiple, diverse uses of mobile devices are being integrated into PC

6   provision in the African Region. A lead priority for mHealth research is the exploration of mHealth to

7   support patient care. However, future mHealth development for PC services in the region need to

8   be mindful of barriers that have been identified. Development and implementation of mHealth

9   approaches need to mitigate, for example, the lack of access to hardware and software to host

10   mHealth approaches, alongside not having adequate expertise to support mHealth use as part of PC

11   service delivery. These barriers may be associated with potential additional costs, at least during

12   initial implementation.

13   A recent review of mHealth use in NCD care across low- and middle-income settings noted that

14   studies currently lack comparator arms, clinical endpoints, or are of short duration[34]. However, it is

15   promising that there has been an increase in the registration of clinical trial protocols of large-scale,

16   multidimensional mHealth interventions[28]. Important work to explore user perspectives is beginning

17   as part of early piloting [35] and qualitative research[36]. Furthermore, initiatives led by the WHO

18   Collaborating Centre on Research and Capacity Strengthening of Health Policy, Governance and

19   Services, and the WHO Collaborating Centre for Palliative care, policy and rehabilitation, are

20   beginning to explore the development and assessment of mHealth in PC services in the African

21   Region.. To date, no research has explored how and why PC patients in this region might interact

22   with mHealth approaches and where there could be value for them. For mHealth to support

23   evaluation and adaptation of services to accommodate rising demands from NCDs, user engagement

24   with patients (such as those with cancer) and their caregivers is an essential next step to inform its

25   design and development. Capturing the needs of end-user perspectives (including those of health

1   professionals) is crucial to health technology development[37] and to understanding contextual factors

2   surrounding implementation[38]. Of equal importance is the need to explore issues related to the

3   privacy, safety and security of data and its transfer. These are issues being faced by researchers and

4   practitioners globally and are a key challenge for patient-centred approaches to mHealth, with calls

5   for international cooperation to form codes of practice and amend regulatory conditions[39].

6   Varied and widespread use of mHealth activities were reported in the survey. To share information

7   on current activities, facilitate collaboration and avoid duplication of mHealth efforts at this early

8   stage, APCA has initiated a mHealth Research Network. The network provides updates on mHealth

9   development in the region and enables PC services to disseminate information about their current

10   mHealth activities with the opportunity to share their experiences. There is a need to now expand

11   the network, ensure representation of PC providers delivering services in a diverse range of settings

12   across the African Region and continue to develop mHealth evaluation research. The emerging

13   health informatics environment across the African Region may then facilitate the transfer and

14   sharing of feasible and effective mHealth approaches. District and national health information

15   systems (HIS) strengthening projects across the region suggests an environment conducive to

16   technology development for healthcare delivery[40]. HIS are being built using similar software

17   platforms, minimising issues around interoperability, such as how data gathered from mobile

18   phones can be used to supply information. Recent recommendations for strengthening health-

19   systems functions to expand access to PC and pain relief included incorporating PC and pain relief

20   access, quality, and financing indicators into health information systems.[41] Furthermore, supporting

21   links between PC services and district and national HIS could help to build a clearer picture of the

22   burden of advanced disease requiring PC across the region.

23   This study has some limitations. Participants were required to have internet access to participate in

24   the survey. This approach may have precluded participation of rural services without internet access

25   that may be utilising mHealth approaches. Additionally, identification of participants occurred

1   through email-based mailing lists developed by APCA. This was crucial for contacting a wide range of

2   PC providers across the region. However, providers and national associations working with APCA

3   represent established PC services and those utilising electronic communication. Those working in

4   services or countries where PC is being delivered less formally may not be represented, alongside

5   providers who do not rely n electronic communication. Future approaches to surveying PC providers

6   may need to explore alternative modes to support wider participation.

7   This early stage of mHealth development in PC services in the African Region could benefit from

8   adopting structured and evidence-based approaches to mHealth development and piloting[42]. This

9   should be accompanied by efforts to develop or scale-up technology-based approaches that align

10   with the unmet needs of intended end users and priority areas for PC development in the African

11   Region. For example, the need to increase PC education in the African Region has been well

12   documented.[5, 26, 43, 44] Gathering a deeper understanding of the multiple mHealth approaches to

13   training and education identified in this study could inform feasible options for expanding access

14   through flexible teaching formats. For patients too, mHealth approaches present opportunities to

15   explore, for example, integration of patient-reported data from PC services into electronic

16   information systems. In the United States this has been shown to improve the scale, efficiency and

17   accuracy of data collection[12]. Adopting mHealth approaches in the African Region could help to

18   determine the experience of patients in receipt of PC, such as those with cancer and other NCDs,

19   and explore how best to adapt services to meet their needs. Alongside collection of data from

20   patients, such work should also explore how mHealth approaches can deliver meaningful

21   information and resources directly to patients and their caregivers. With mHealth activities reported

22   across PC in the African Region, and priorities for its development emerging, unified and

23   collaborative working needs to be encouraged to determine how mHealth can best support the

24   delivery of care for increasing numbers of patients and their caregivers requiring PC.

1 **Declarations**

2

3 **Ethics approval and consent to participate**

4 Ethical approval for the study was obtained from the University of Leeds Research Ethics Committee

5 (reference MREC15-089). Informed consent to participate in the study was obtained from all

6 participants.

7 **Consent to publish**

8 Consent to publish was obtained from all participants prior to completion of the online survey.

9 Consent was obtained via a form presented online and was mandatory for all participants prior to

10 participation in the study.

11 **Availability of data and materials**

12 The datasets used and analysed during the current study are available from the corresponding

13 author on reasonable request.

14 **Competing interests**

15 The authors declare no conflict of interest.

16 **Funding**

17 This work was supported by the University of Leeds Wellcome Trust Institutional Strategic Support

18 Fund.

19 **Authors' contributions**

20 MA developed the survey approach and content, with support from EN and RP. MA led data

21 collection, facilitated by EN. All authors were involved in drafting of the manuscript and have

1   approved the final version for publication. All authors agree to be accountable for all aspects of the

2   work in ensuring that questions related to the accuracy or integrity of any part of the work are

3   appropriately investigated and resolved.

4   **Acknowledgements**

1 **References**

2 1.   Knaul FM, Farmer PE, Bhadelia A, et al. Closing the divide: the Harvard Global Equity

3 Initiative-Lancet Commission on global access to pain control and palliative care. Lancet. 2015; 386:

4 722-4.

5 2.   Lynch T, Connor S and Clark D. Mapping levels of palliative care development: a global

6 update. J Pain Symptom Manage. 2013; 45: 1094-106.

7 3.   Downing J, Grant L, Leng J, et al. Understanding Models of Palliative Care Delivery in Sub-

8 Saharan Africa: Learning From Programs in Kenya and Malawi. Journal of Pain and Symptom

9 Management. 2015; 50: 362-70.

10 4.   Herce ME, Elmore SN, Kalanga N, et al. Assessing and Responding to Palliative Care Needs in

11 Rural Sub-Saharan Africa: Results from a Model Intervention and Situation Analysis in Malawi. PLOS

12 ONE. 2014; 9: e110457.

13 5.   Harding R, Selman L, Powell RA, et al. Research into palliative care in sub-Saharan Africa.

14 Lancet Oncology. 2013; 14: e183-e8.

15 6.   Powell RA, Ali Z, Luyirika E, Harding R, et al. Out of the shadows: non-communicable diseases

16 and palliative care in Africa. BMJ Supportive & Palliative Care. 2017; 7: 128-132.

17 doi:org/10.1136/bmjspcare-2014-000751.

18 7.   Logie DE and Harding R. An evaluation of a morphine public health programme for cancer

19 and AIDS pain relief in Sub-Saharan Africa. BMC Public Health. 2005; 5: 82.

20 8.   Fraser BA, Powell RA, Mwangi-Powell FN, et al. Palliative Care Development in Africa:

21 Lessons From Uganda and Kenya. Journal of Global Oncology. 2018: 1-10.

1   9.   Ostherr K, Killoran P, Shegog R et al. Death in the Digital Age: A Systematic Review of

2   Information and Communication Technologies in End-of-Life Care. Journal of Palliative Medicine.

3   2015; 19: 408-20.

4   10.   Allsop MJ, Taylor S, Mulvey MR, et al. Information and communication technology for

5   managing pain in palliative care: a review of the literature. BMJ Supportive & Palliative Care. 2014; 5:

6   481-9.

7   11.   Dy SM, Roy J, Ott GE, et al. Tell Us™: A Web-Based Tool for Improving Communication

8   Among Patients, Families, and Providers in Hospice and Palliative Care Through Systematic Data

9   Specification, Collection, and Use. Journal of Pain and Symptom Management. 2011; 42: 526-34.

10   12.   Chung AE and Basch EM. Incorporating the patient's voice into electronic health records

11   through patient-reported outcomes as the "review of systems". Journal of the American Medical

12   Informatics Association. 2015; 22: 914-6.

13   13.   Girault A, Ferrua M, Lalloue B, et al. Internet-based technologies to improve cancer care

14   coordination: current use and attitudes among cancer patients. European Journal of Cancer. 2015;

15   51: 551-7.

16   14.   Taylor S, Allsop MJ, Bekker HL, et al. Identifying professionals' needs in integrating electronic

17   pain monitoring in community palliative care services: An interview study. Palliative Medicine. 2017;

18   31(7): 661-670. doi:10.1177/0269216316677470.

19   15.   Folaranmi T. mHealth in Africa: challenges and opportunities. Perspectives in Public Health.

20   2014; 134: 14-5.

21   16.   Aranda-Jan CB, Mohutsiwa-Dibe N and Loukanova S. Systematic review on what works, what

22   does not work and why of implementation of mobile health (mHealth) projects in Africa. BMC Public

23   Health. 2014; 14: 188.

1   17.   Grant L, Brown J, Leng M, et al. Palliative care making a difference in rural Uganda, Kenya

2   and Malawi: three rapid evaluation field studies. BMC Palliative Care. 2011; 10: 8.

3   18.   Curioso WH and Mechael PN. Enhancing 'M-health' with south-to-south collaborations.

4   Health Affairs. 2010; 29: 264-7.

5   19.   Frenk J and Gómez-Dantés O. False dichotomies in global health: the need for integrative

6   thinking. Lancet. 2016; 389: 667-70.

7   20.   Harding R, Selman L, Agupio G, et al. Prevalence, burden, and correlates of physical and

8   psychological symptoms among HIV palliative care patients in sub-Saharan Africa: an international

9   multicenter study. Journal of Pain and Symptom Management. 2012; 44: 1-9.

10   21.   Harding R, Powell RA, Namisango E, et al. Palliative care-related self-report problems among

11   cancer patients in East Africa: a two-country study. Supportive Care in Cancer. 2014; 22: 3185-92.

12   22.   Farrant L, Gwyther L, Dinat N, et al. The prevalence and burden of pain and other symptoms

13   among South Africans attending highly active antiretroviral therapy (HAART) clinics. South African

14   Medical Journal. 2012; 102: 499-500.

15   23.   Moens K, Higginson IJ and Harding R. Are there differences in the prevalence of palliative

16   care-related problems in people living with advanced cancer and eight non-cancer conditions? A

17   systematic review. Journal of Pain and Symptom Management. 2014; 48: 660-77.

18   24.   Downing J, Simon ST, Mwangi-Powell FN, et al. Outcomes 'out of africa': the selection and

19   implementation of outcome measures for palliative care in Africa. BMC Palliative Care. 2012; 11: 1.

20   25.   Dawson J, Doll H, Fitzpatrick R, et al. The routine use of patient reported outcome measures

21   in healthcare settings. BMJ. 2010; 340: c186.

1   26.   Rhee JY, Garralda E, Namisango E, et al. Factors Affecting Palliative Care Development in

2   Africa: In-Country Experts' Perceptions in Seven Countries. Journal of Pain and Symptom

3   Management. 2018 [epub ahead of print]. doi: 10.1016/j.jpainsymman.2018.01.009.

4   27.   Beratarrechea A, Lee AG, Willner JM, et al. The Impact of Mobile Health Interventions on

5   Chronic Disease Outcomes in Developing Countries: A Systematic Review. Telemedicine and e-Health.

6   2013; 20: 75-82.

7   28.   Peiris D, Praveen D, Johnson C et al. Use of mHealth Systems and Tools for Non-

8   Communicable Diseases in Low- and Middle-Income Countries: a Systematic Review. Journal of

9   Cardiovascular Translational Research. 2014: 1-15.

10 29.   Betjeman TJ, Soghoian SE and Foran MP. mHealth in sub-Saharan Africa. Journal of

11 Telemedicine and Applications. 2013; 2013: 6.

12 30.   Allsop MJ, Powell RA and Namisango E. The state of mHealth development and use by

13 palliative care services in sub-Saharan Africa: a systematic review of the literature. BMJ Supportive &

14 Palliative Care. 2016 [epub ahead of print]. doi: 10.1136/bmjspcare-2015-001034.

15 31.   El Ansary M, Nejmi M, Rizkallah R, et al. Palliative care research in northern Africa. European

16 Journal of Palliative Care. 2014; 21: 98-100.

17 32.   Connor SR and Bermedo MCS. Global Atlas of Palliative Care at the End of Life. London:

18 Worldwide Palliative Care Alliance, 2014.

19 33.   Labrique AB, Vasudevan L, Kochi E, et al. mHealth innovations as health system

20 strengthening tools: 12 common applications and a visual framework. Global Health: Science and

21 Practice. 2013; 1: 160-71.

1   34.   Bloomfield GS, Vedanthan R, Vasudevan L, et al. Mobile health for non-communicable

2   diseases in Sub-Saharan Africa: a systematic review of the literature and strategic framework for

3   research. Globalization and Health. 2014; 10: 49.

4   35.   Namisango E, Ntege C, Luyirika EBK, et al. Strengthening pharmaceutical systems for

5   palliative care services in resource limited settings: piloting a mHealth application across a rural and

6   urban setting in Uganda. BMC Palliative Care. 2016; 15: 20.

7   36.   van Gurp J, Soyannwo O, Odebunmi K, et al. Telemedicine's Potential to Support Good Dying

8   in Nigeria: A Qualitative Study. PLOS ONE. 2015; 10: e0126820.

9   37.   Shah SG, Robinson I and AlShawi S. Developing medical device technologies from users'

10 perspectives: a theoretical framework for involving users in the development process. International

11 Journal of Technology Assessment in Health Care. 2009; 25: 514-21.

12 38.   Opoku D, Stephani V and Quentin W. A realist review of mobile phone-based health

13 interventions for non-communicable disease management in sub-Saharan Africa. BMC Medicine.

14 2017; 15: 24.

15 39.   European Commission. Green paper on mobile health ("mHealth"). Digital Agenda for

16 Europe 2014. European Commission, 2014.

17 40.   Mutale W, Chintu N, Amoroso C, et al. Improving health information systems for decision

18 making across five sub-Saharan African countries: Implementation strategies from the African Health

19 Initiative. BMC Health Services Research. 2013; 13: S9.

20 41.   Knaul FM, Farmer PE, Krakauer EL, et al. Alleviating the access abyss in palliative care and

21 pain relief; an imperative of universal health coverage: the Lancet Commission report. Lancet. 2017

22 [epub ahead of print]. doi:org/10.1016/S0140-6736(17)32513-8.

1   42.   French SD, Green SE, O'Connor DA, et al. Developing theory-informed behaviour change

2   interventions to implement evidence into practice: a systematic approach using the Theoretical

3   Domains Framework. Implementation Science. 2012; 7: 38.

4   43.   Downing J, Knapp C, Muckaden MA, et al. Priorities for global research into children's

5   palliative care: results of an International Delphi Study. BMC Palliative Care. 2015; 14: 36.

6   44.   Wiener L, Weaver MS, Bell CJ et al. Threading the cloak: palliative care education for care

7   providers of adolescents and young adults with cancer. Clinical Oncology in Adolescents and Young

8   Adults. 2015; 5: 1-18.