

STUDY PROTOCOL

Protocol for a mixed-methods exploratory investigation into the role of health information technology for the provision of cancer care in Indonesia

[version 2; peer review: 1 approved, 1 approved with reservations]

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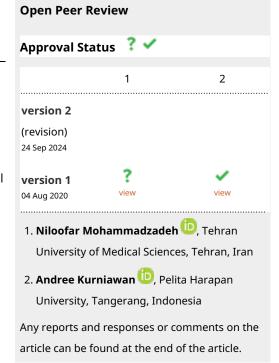
Abstract

Background

Cancer and its management can incur high costs, high risks and high demand. In Indonesia, there remains gap in the availability of national cancer data despite the establishment of a National Committee for Cancer Control. Multiple pilot projects have been developed by the Ministry of Health to improve the delivery of care, including interventions utilising digital health approaches and integrated referral information systems. However, it is not yet clear to what extent these approaches influence patient management or the experience of cancer patients themselves. This research aims to explore the current role of health information technology (HIT) in the provision of services and treatments for patients with cancer from primary to tertiary healthcare centres in Yogyakarta, Indonesia.

Methods

The study will adopt an observational mixed-methods single case study design of health facilities involved in the delivery of cancer services in a sub-national health system. We will collect data through face-to-face interviews with a range of health professionals involved in the delivery of cancer care. Patients will be interviewed to share their



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views and experiences of the existing cancer referral system and communication with health facilities. Alongside interviews, we will undertake an analysis of routine data from participating health facilities to assess gaps in existing information systems. Data analysis will include framework analysis for qualitative data alongside descriptive analyses of quantitative data. Findings will be used to inform conceptual maps to be presented as part of Theory of Change workshops focused on understanding how the existing cancer referral system works, why and for whom, with a focus on future refinement and intervention development.

Conclusion

Our findings will inform critical thinking around the design, implementation, adaptation, and evaluation of existing systems. Through early engagement and participation of key stakeholders and project partners, we intend that findings will have immediate utility.

Keywords

Neoplasms, Medical Informatics, Referral and Consultation, Indonesia



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REVISED Amendments from Version 1

The changes made from version 1 to 2 comprise of 1) edits to column names in Table 2 to clarify that data being presented in the third column relates to the total number of different facility types that are present in the region in which the research will take place (i.e. Yogyakarta), 2) additional text added to the 'Sample selection' section to detail how participants will be identified during recruitment to the project and to specify that a mix of items will be included in the topic guide for child participants with caregivers to be present during interviews, 3) further text added to the 'Health professional interviews' section to acknowledge limitations relating to the inclusion of a small number of general practice sites, 4) edits to the topic guide in Table 6 to specify which items are for adult or child participants alongside variations in the wording of questions based on the participant type (i.e., whether an adult or child), and 5) minor typographical corrections throughout the manuscript to align the presentation of text (e.g. ensuring all words were capitalised in the sub-heading 'Theoretical Frameworks Underpinning

Any further responses from the reviewers can be found at the end of the article

Introduction

In 2018, there were an estimated 348,809 cases and 207,210 deaths from cancer in Indonesia, projected to increase to 575,814 cases and 366,567 deaths annually by 20401. After stroke, cancer has been reported as a leading cause of death in the country². A cancer diagnosis can be potentially disastrous, with over 75% of patients with cancer in the Southeast Asia region experiencing death or financial catastrophe within one year3. The limited provision of cancer care in Indonesia was reflected in the Cancer Preparedness Index, an initiative in 20194 to highlight differences in cancer policy and systems between countries and how they relate to outcomes. Indonesia was rated 25th of 28 countries evaluated⁵, largely influenced by limitations in its service availability, workforce, and infrastructure, alongside a lack of cancer research. The consequences of a cancer diagnosis and the limited existing provision provide compelling evidence for the need to develop policies to improve access to and provision of cancer care in the country.

Cancer and its management can incur high costs, high risks and high demand⁶. According to WHO guidelines⁷, health systems should aim to provide a holistic approach to the management of cancers to prolong lives through early detection, timely diagnosis and adequate treatment, alongside providing palliative care for advanced cancer, carried out within the context of a comprehensive cancer control plan8. For Indonesia, where there is an increasing cancer burden, the Ministry of Health has yet to officially endorse the National Cancer Control Plan9. The current National Cancer Control Plan⁹ contains 13 strategic goals, including the implementation of national cancer treatment guidelines, the development of palliative care provision, and the establishment of information and communication technology (ICT) systems to unpin developments in cancer provision¹⁰. The last of these is driven in part by the need to enhance data on cancer in the country.

A National Committee for Cancer Control was established in 1989, with one of its programs to develop a cancer registry and

provide national cancer data. However, there remain gaps in the availability of national cancer data¹¹. Attempts to develop a national population-based cancer registry have been conducted but stopped due to various reasons¹², until it was re-established in 2016. Previously, cancer registries were more often conducted as pathology-based or hospital-based site-specific registries^{11,12}. The more common sources for national cancer data are annual reports from the Ministry of Health, including the Indonesian Health Profile, Indonesian Basic Health Research, and secondary data from Indonesian Universal Health Coverage^{13–15}. Ministry of Health publications provide tabular data from the health system, including cancer, but lack granularity with multiple cancer types grouped under one summary figure.

A further driver for ICT development is to leverage its capabilities to overcome distance-time barriers and facilitate participation in global oncology care, education, and research, alongside opportunities to overcome gaps in patient care and clinical expertise¹⁶. Across the spectrum of cancer care, research literature from contexts with differing levels of resource reports the role of digital technology is increasing, with their implementation supporting reductions in costs and increases in workflow efficiency, as well as improving overall health care value, patient outcomes, and quality of life^{7,17–19}. The implementation of digital technologies has been shown to enhance the management of cancer care in promoting patient-centeredness frameworks and improving patient care and safety^{18,19}. A major subtype of technology used within cancer care is health information technology (HIT), which supports the management of health information across computerised systems (e.g. electronic health records, e-prescribing systems) alongside the secure exchange of health information between consumers, providers, payers, and quality monitors²⁰. HIT involves a range of stakeholders to support its coordination and use in providing quality care that can ultimately lead to patient satisfaction²¹. Its use in the context of cancer care can support improvements in coordination of care, shared care planning, person-centred coordination, and coordination between and within teams²². HIT may be advantageous in the context of health systems in low and middle-income countries (LMICs) due to the extensive coordination of care at and across various levels, including the community level, primary care centres, and secondary and tertiary care levels²³.

In Indonesia, multiple pilot projects have been developed by the Ministry of Health to improve the delivery of care, including a mobile phone app to gather data on the health of families and individuals²⁴, integrated referral ICT systems²⁵, integrated telemedicine approaches²⁶ and mobile-phone based data collection approaches for the national health insurance scheme²⁷. Furthermore, various referral applications for use in health care facilities have been developed by the Ministry of Health of the Republic of Indonesia and Badan Penyelenggara Jaminan Sosial (BPJS) Kesehatan (which translates as Social Insurance Administration Organization), a national health insurance provider in Indonesia^{28,29}. More recently, BPJS Kesehatan has required all primary healthcare centres (referred to as Puskesmas in Indonesia) to use P-Care, a cloud-based application aiming to record treatments and services of those covered by BPJS Kesehatan³⁰. Through P-Care, Puskesmas can electronically refer patient information to higher levels of the health system to

facilitate and manage bookings and appointments. The Ministry of Health has also developed an Integrated Referral Information System (SISRUTE) that can help health facilities to support similar vertical referrals across different levels of the health system, especially in the case of emergency and urgent referrals^{25,31}. However, it is not yet clear whether these various technologies improve efficiencies in patient management or improve the experience of patients with certain conditions, such as cancer, that require repeated and frequent visits to health facilities.

Despite being a strategic goal in national planning of cancer control, and its potential value in LMIC settings, such as Indonesia, there has been no research reported that details the existing ICT infrastructure in the delivery of care for patients with cancer. This research seeks to address this gap in knowledge and aims to explore the current role of HIT in the provision of services and treatments for patients with cancer from primary to tertiary healthcare centres. Identifying and mapping existing HIT for cancer care in Indonesia is intended to support critical thinking around the design, implementation, adaptation, and evaluation of existing systems.

Study protocol Methods and analysis Origin of research focus

In April 2019, a multi-stakeholder workshop was hosted by the study authors at Universitas Gadjah Mada (UGM), focusing on research priorities for cancer and digital technology research in Indonesia. The study team comprise applied health researchers with cancer and informatics expertise and experienced oncology clinical academics familiar with cancer provision in Yogyakarta. Attendees included representatives from the Ministry of Health (NCD Directorate), Ministry of Research, Technology and Higher Education, Ministry of Finance, Indonesian Cancer Foundation, independent commercial companies working in cancer care, academics from multiple departments in UGM including Internal Medicine, Surgery, Radiology, Public Health, and Nursing, and oncologists from hospitals in Yogyakarta, Indonesia. During discussions, it was highlighted that digital architecture in cancer care is not well understood in Indonesia. Research priorities highlighted during the workshop included determining available technologies used by cancer services, approaches to determining the quality of care delivery, patient-reported outcomes during and after cancer treatments, the development of palliative care approaches,

where there is scope for development. Patient and public involvement

We consulted the Indonesian Cancer Foundation (ICF), Yogyakarta branch, on the design of the research study. The ICF is a non-governmental organization that aims to support the Government of Indonesia in its delivery of cancer care, by taking on promotional, preventive, as well as rehabilitative measures and supportive activities. The ICF also advocates on behalf of patients with cancer and their caregivers. We

and eliciting patient perspectives on the delivery of care.

The proposed work is in response to the first priority, seeking

to map the digital architecture of a defined region of Indonesia,

to understand how it currently supports cancer care delivery and

consulted the ICF about the questions for participants to make sure that the topic headings were exhaustive and capture the patient journey from the beginning of care and that the content of topic guides was acceptable to patients. The ICF supported engagement with patient groups and facilitated discussions on the types of study participants that were sought and the representativeness of the target population. We also conducted a preliminary discussion with healthcare professionals to inform the development of the topic guide for the study, ensuring the topic guide captures the flow of patients and the information processes undertaken by health facilities. During the dissemination of findings, we will consult with patient advocacy groups to i) guide key messages from findings of relevance to patients and members of the public; ii) support with developing plain language summaries of study findings for dissemination, and iii) identify which communication channels might be used to disseminate study findings for patient and public audiences.

Study design

The study will adopt an observational mixed-methods single case study design³² of health facilities involved in the delivery of cancer services at the primary, secondary, and tertiary levels in a sub-national health system. For a country implementing decentralization, health politics at a sub-national level is highly influenced by the policy at the national level. An observational mixed-methods single case study design is well-placed to support the development of new theory³². We will use the approach to support the development of an underpinning theory that reflects the current structure, content and use of IT infrastructure for referrals within cancer care in Yogyakarta, Indonesia.

Theoretical frameworks underpinning research

Multiple theoretical frameworks have been developed that may have relevance to exploring and understanding HIT adoption and implementation in the health sector^{33–36}. Within this study, we will draw on the socio-technical model³⁷, one of the models used to review HIT comprehensively from various dimensions in the health system. The socio-technical model frames the focus of project activities to focus on multiple, interacting and key components to better understand HIT for cancer care in Yogyakarta. Eight interrelated dimensions of the socio-technical model will be explored: 1) hardware and software computing infrastructure, 2) clinical content, 3) human-computer interface, 4) people, 5) workflow and communication, 6) internal organizational policies, procedures, and culture, 7) external rules, regulations, and pressures, and 8) system measurement and monitoring³⁷. While these are presented as single components, the eight specific dimensions are multiple, interacting components with non-linear, emergent, dynamic behaviour (i.e., small changes in one aspect of the system lead to small changes in other parts of the system under some conditions, but large changes at other times). The relationships and dependencies across the dimensions of the HIT for cancer referrals in Yogyakarta will be explored during the intervention development phase of the project. We will develop conceptual maps to depict identified relationships and relay these to system users and policymakers to validate their content and guide discussions around the prioritisation of intervention design to refine and develop existing HIT for cancer referrals.

A recent publication of the infrastructure supporting cancer referral systems in Indonesia has been published³⁸. The framework used is based on enterprise architecture (EA) which refers to the Open Group Architecture Framework (TOGAF). This will be used to provide a detailed explanation regarding the structure and key components of the referral system as it relates to cancer, alongside providing insight into the first of the eight dimensions of the socio-technical model to be explored; hardware and software computing. In general, cancer referrals in Indonesia are conducted according to hospital classification type within the national health insurance framework. Although the study will be limited to Yogyakarta, the system observed in this study should also be able to represent the national cancer referral process with slight differences between regions caused by the availability of services and providers in each area.

Health system context

The cancer control program in Indonesia predominantly focuses on promotion and preventative efforts (e.g. increasing knowledge for the public about approaches to cancer prevention and known risk factors) and early detection programs at the primary care level³⁹. Delivery of care is across general and specialty hospitals which the Indonesian government classifies into several classes (A, B, C, D) based on facilities and the services provided by the hospitals (Table 1)40. Class A hospital is the highest level. This category was established for referral purposes⁴¹. For cancer service delivery, management is divided across primary, secondary, and tertiary referral facilities. Cancer services in Indonesia are classified based on the level of service, namely primary care (examination and or basic medical action in the health sector of care/clinic/health centre in the primary health care), secondary care (access to specialist doctors in D type/C type/B type hospitals), tertiary care (medical examination and or treatment performed by oncology subspecialist in A type hospitals)⁴².

The provision of services as part of cancer care varies across different levels⁴³. Services at the primary health care level involve education and counselling related to cancer, screening of cancer, providing first aid in cancer emergencies, case finding and passing referrals, and registering cancer data⁴⁴. Services at the secondary level involve further handling of patient referrals from primary health facilities, managing cancer emergencies, conducting special cancer medical examinations and actions,

establishing cancer diagnoses, and multidisciplinary teams, providing health lifestyle advice, and conducting cancer data regimens. Services at tertiary level services include conducting primary and secondary checks related to cancer, following up on patient referrals from secondary health facilities and emergency cancer cases, advanced diagnostic investigations, follow-up examinations, integrated management, special medical actions, referrals, and registration of cancer data⁴⁵.

Using data from 2015, there were a total of 2,488 hospitals in Indonesia, comprising both general (n = 1,949) and speciality (n = 539) hospitals. As a first step to explore the role of HIT in cancer care, this study focuses on the Special Region of Yogyakarta, a region of Indonesia located on the island of Java. Reflective of population maldistribution in Indonesia, 70% of its inhabitants are condensed on the island of Java, which equals 11.5% of the land area of Indonesia, while the remainder is sparsely distributed across a further 17,000 islands⁴⁶. The current population of the Special Region of Yogyakarta was 3,656,108 in the most recent 2019 census⁴⁷.

Setting

The study will be conducted in the Special Region of Yogyakarta, Indonesia, across nine facilities supporting the delivery of cancer care. The facilities will be selected through stratified purposeful sampling intended to reflect variation among different levels of the health system (i.e. primary care, D type hospital, C type hospital, B type hospital, and A type hospital). The selected sample will be based on the maturity of the referral system within the healthcare center and whether the health facility is active in the national cancer registry network. A sampling frame will ensure the representation of health facilities at each level of care. This includes Primary Health Care Facilities (FKTP) and Advanced Referral Healthcare Facilities (FKRTL). All participating facilities will be based in the Yogyakarta special province, with an overview of facility groupings by health ministerial decree outlined in Table 2⁴⁸.

Participants

The study will recruit staff in healthcare facilities, both those involved in the management of cancer referral systems and those who are providing care to cancer patients (Figure 1). In this study, patients will also be recruited to provide insights into their experience engaging with the referral service system and maintaining communication with the service provider/health facilities.

Table 1. Classification of hospital type in Indonesia.

Hospital Type	Emergency service	General practitioners	Basic medical specialty*	Supporting medical specialty**	Other medical specialties	Dental specialty
A type	V		V	V	V	V
B type	V		V	V	V	V
C type	V	V	V	V	V	V
D type	V	V	V	V		

^{*}including internal medicine, paediatrics, surgery, and obstetrics and gynaecology

^{**}including anaesthesiology, radiology, clinical pathology, anatomical pathology, and medical rehabilitation

Table 2. Selected sample of health facilities in the special region of Yogyakarta.

Type of Health Facilities	Category	Total Number of Facilities in Yogyakarta	Selected Facilities to be Involved
A type Hospital	Tertiary	3	1
B type Hospital	Tertiary	12	1 public & 1 private
C type Hospital	Secondary	32	1 public & 1 private
D type Hospital	Secondary	34	1 public & 1 private
Other (Specialized) Hospital	Secondary	2	0
Primary health care facility	Primary	306	2

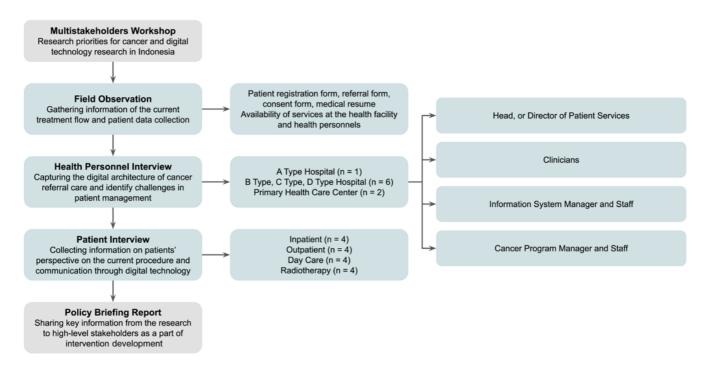


Figure 1. Data collection process.

Sample selection

Following the selection of health facilities, interviews with staff and patients will be conducted within each of the participating health center sites. Participants will be purposively sampled to ensure the representation of perspectives to inform existing referral processes. This will include both health facility staff who have a direct role in cancer referral management and patients with cancer. Purposive sampling will ensure the selection of participants likely to provide richly-textured information relating to referral processes. The research team will liaise with the Head or Director of Patient Services at each facility to support the identification of eligible health professionals. The research will liaise with clinical staff supporting patients with cancer to identify and support the recruitment of patient participants.

Inclusion criteria for health facility participants include working in cancer care at any of the health facilities being recruited from and having worked in their role for 1 or more years. We will seek representation of participants across health facilities involved in the referral and management of patients with cancer, including representation across the range of staff types working within facilities (i.e. service directors, clinicians, information system managers and cancer program managers). A sampling frame will be developed for selecting patients at each facility, including characteristics of age (adults and children), sex (males and females), cancer type and service currently accessing (including inpatient, outpatient, one-day care, and radiotherapy). This will capture variation in the flow and processes of patients across clinical settings. For interviews with child participants, a mix of items will be included to elicit

responses from both child participants and their caregivers who will be present during the interview. Only participants who are able to consent or assent to participation and have no communication impairment will be approached to participate. The criteria and sampling size of the patients are detailed in Table 3.

The sample size for health facility and patient participants to be recruited across sites was determined by the exploratory nature of the study and pragmatic considerations (i.e. resource constraints in terms of research budget and research team size). The selection of sites to ensure information-rich data collection was guided through consultation with the District Health Office. The adequacy of data quality and richness being gathered during interviews will be monitored through regular team meetings. A sampling frame for health facility staff is outlined in Table 4 and for patient participants in Table 3. We will consult with the clinical teams in each cancer unit in participation sites to support patient recruitment.

Qualitative data collection

Field observations

We will carry out participant observation in the field prior to interviews with health professionals to collect information on the routine method and variety of patient data collected in the health facilities. We will explore a range of forms used in health-care centers (i.e. patient registration form, referral form, consent form, and medical resume). We will also gather data on the availability of radiotherapy and chemotherapy services, including details on the average daily visits, available beds, duration and frequency of the treatments, number of human resources, and the equipment used. The output from the observation will form the basis of interviews with the health personnel.

Health personnel interviews

Semi-structured face-to-face interviews will be conducted with staff involved in providing care for cancer patients. This includes hospital managers or directors of the patient service, clinicians, and health information system managers. Access

Table 3. Sampling criteria for patients.

Inclusion and exclusion criteria		Cancer service	Number of Patients*	Number of Health Facilities	Total Number of Patients
Inclusion Criteria Cancer patients undergoing treatment with a stable condition or caregiver of child patient undergoing treatment with a stable condition.	Sampling across health facility types	Inpatient Outpatient	4	9	36 36
Exclusion Criteria Patients with communication and/or cognitive impairment.		One-day Care Radiotherapy	4	3** 1***	12 4
Patients unable to consent to participation or deemed too unwell to participate by clinical team.					

^{*}Each group of patients should represent the distribution of age (adult and children) and sex (male and female)

Table 4. Intended recruitment of hospital personnel for interview.

Selected Staff	A Type Hospital (n = 1)	B Type Hospital (n = 2)	C Type Hospital (n = 2)	D Type Hospital (n = 2)	Primary healthcare facility (n = 2)	Total
Head or Director of Patient Services	1	2	2	2	2	9
Clinicians	2	4	4	4	4	18
Information System Manager and Staff	2	4	2	2	2	12
Cancer Program Manager and Staff	2	2	2	2	2	10
Total	6	12	10	10	10	48

^{**}Only for A-type and B-type hospitals with one-day care services.

^{***}Only for A-type hospitals with radiotherapy services.

to respondents will be through a written letter directed to the management of healthcare facilities. This interview will be conducted with staff from various areas because of the interrelation between units in conducting cancer care, including referral services. Data will be collected from 48 in-depth interviews. Where face-to-face interviews are not possible, interviews will be offered via telephone or video calls in place of meeting face-to-face.

Prior to the interview, written consent will be obtained to record and transcribe the interview. The one-hour semi-structured interviews will be conducted face-to-face by an interviewer; a note-taker will be present for the duration of the interview. Interviewers will record observations about the circumstances of the interview, summarise key opinions and factors that arise, and note considerations for modifying the topic guide for subsequent interviews.

A topic guide and questions have been developed to guide the interview (Table 5). Interviews will focus on the implementation of the existing HITs and cancer registry, the workflow and interoperability, current policies related to HIT, barriers in

Table 5. Topic guide for health personnel interview.

Topic Heading	Questions	Socio-technical dimension
Current available information system and data related to cancer treatments	What information and data do you have available to inform your management of patients with cancer (e.g. demographics, history of illness, treatment interventions received, clinical records, case files)?	Clinical Content
	How do you use the available data? How useful is the data?	Workflow and Communication
	Is there a hospital information system running at the hospital? Which services use the information system?	Hardware and Software Computing Infrastructure
	How do you use the information system (e.g. update or review patient records, service evaluation, audit)?	System Measurement and Monitoring, Workflow and Communication
	Which data is included to guide and support patient care (if not already mentioned above)?	People
	Are evaluations carried out by hospitals related to cancer services? If so, what are these?	System Measurement and Monitoring
	Are there any specific technology-based systems for cancer patients? (E.g.: cancer registry, special booking/ registration system, e.g. for radio/chemotherapy services, or communication services for patients with by text message / phone call)	Hardware and Software Computing Infrastructure
	Does the hospital have a call center? If yes, how is it managed and for which types of services is the call center applicable?	People
	Does the hospital develop or use social media to communicate with patients?	People
Challenges in the use of current information systems, including means	Is there any additional data that you need (and don't have access to) that could help you manage a patient with cancer?	Clinical Content
or data to support cancer patient management	What issues exist in the operation of the current IT systems? What do you feel may be the factors causing or affecting these issues (e.g. interoperability, resources and cost)?	Human Computer Interface
	What are the main problems in registration management, booking services, tracking, and managing communication between cancer patients and hospitals?	People, Human Computer Interface, Workflow and Communication
The referral system across different level of health facilities	Has the hospital exchanged data electronically with other health facilities? If not yet, does an electronic exchange of data need to be developed for referral and communication systems for cancer patients between health facilities?	Workflow and Communication
	Are there standard procedures to refer or admit patients?	Internal Organizational Policies, Procedures, and Culture
	Has the hospital bridged with the national health insurance (i.e. the Badan Penyelenggara Jaminan Sosial (BPJS) scheme)? What data has been exchanged electronically with BPJS?	Workflow and Communication

Topic Heading	Questions	Socio-technical dimension	
Regional or national reporting system	Are there any formalized reporting systems with local or national authorities? How often are the hospitals required to report?	External Rules, Regulations, and Pressures	
	What information do you report to local and national authorities (e.g. number of patients seen, age, diagnoses of patients)?	External Rules, Regulations, and Pressures	
Opinions or recommendation to support cancer information sharing across all healthcare levels considering the arising problem.	What do you feel are the innovations, if any, related to supporting the collection or sharing of data and information for cancer services?	Workflow and Communication, People, Human Computer Interface	

HIT operation and sharing across different units, and innovation strategies to address the challenges. We will use an interview topic guide to ensure the coverage of our research questions. Evidence from field observations will also be incorporated into interviews as a basis for discussion regarding treatment options and availability. The output of interviews will be centred around the existing and ideal cancer referral pathway, data management, and reporting mechanism to the central government. We anticipate a discussion on the possible gaps in the current pathway, including but not limited to the HIT architecture, digital literacy of the personnel, and human resources constraints. We acknowledge that only a small proportion of all general practices are sought for involvement in the study. This is an exploratory study, where we are seeking to understand a range of stakeholder experiences and ICT infrastructure being used. A small sample of general practice sites will enable the elicitation of views but may not fully capture the range of ICT approaches and current experiences in this setting.

Patient interviews

For adult patient participants, in-depth interviews will focus on an exploration of participants' experiences of using a referral service system and how they maintain communication with the service provider, current use of digital technologies (such as smartphones), and gaps in provision that participants feel would improve or enhance existing service provision for patients with cancer. For child participants, the interview will be conducted with the caregiver to explore their experiences of using the referral systems. The interviews will be conducted following the topic guide detailed in Table 6.

We will conduct face-to-face interviews with cancer patients. Caregivers, typically family members, often accompany patients to clinical appointments and are involved in the decision-making process in Indonesia⁴⁹. As such we will be flexible about whether interviews are conducted with individual patients or with their caregivers present. All participants will be required to sign a consent form to participate in the study. Before the interview, where participant literacy levels are high, written consent will be obtained to record and transcribe the interview. Where literacy is low, verbal consent to record and transcribe the interview will be obtained from the participant. For those providing verbal consent, participants will

be asked whether they would like to have a trusted relative or friend as their witness. The 30-minute-interviews will be conducted by an interviewer; As with health professional interviews, interviews will be held by telephone or video calls where face-to-face meetings are not possible.

Audio recording and electronic copies of consent forms will be stored in password-protected files using the Microsoft OneDrive platform. An electronic copy of consent materials will be made as soon as possible following an interview and once an electronic version has been created, paper copies will be destroyed. Only research team members will have access to the OneDrive platform folder set up for the study. On completion of this study, all electronic data on the OneDrive folder, (i.e. electronic copies of consent forms and audio recordings of interviews), will be moved to an electronic archive for 5 years prior to being permanently destroyed. Following completion of the study, we will assess the suitability of wider sharing of research data, once deidentified, via a research data repository. All study participants will be assigned an identification code, which will be delinked from their identity across all study documentation.

Quantitative data collection

We will collect the summary of the distribution and demographic data of cancer patients from hospitals and Puskesmas routine reports, along with data from the district health office; Data will be drawn from the report of the 24-month period prior to the study taking place in May 2020. We will collect the number of admitted and referred cancer patients in the last two years. Variables included will be the type of admission (emergency room, inpatient, outpatient), referral status (referred or not), and the outcome (discharged, died, referred). The data will be used to determine patterns of referral as reflected through routine data and explore whether these data can inform where gaps exist in the existing referral system.

Data analysis

Qualitative data. Interviews will be transcribed verbatim before being imported into NVivo 12 software for deductive framework analysis. An initial exploration and charting of pseudonymised transcripts will be undertaken (AE) through a process of line-by-line coding. Initial coding will be conducted using a random set of transcripts (n=3) for each of the three key stakeholder groups (i.e. patients, health professionals involved

Table 6. Topic guide for patient interview.

Topic Heading	Questions
Deticated association in the administration services	Please can you tell me about when you first visited this health facility.*
Patients' experience in the admission process and communication with health facilities	How often do you visit the facility?* Are there are any things that you like about the facility? If so, what are they? + Are there are any things that you do not like about the facility? If so, what are they? +
	What was your experience of the registration procedure for treatment in this health facility?
	Were you (or <child name="" participant=""> for child participant interviews) admitted to different health facilities prior to this? If so, what was your experience of being referred to this facility?</child>
	How do you usually communicate with the health facility?
	Do you use any technology devices for your (or <child name="" participant=""> for child participant interviews) cancer care (e.g. look for information or health services)?</child>
	Is there any special application or call centers that you use to support how you (or <child name="" participant=""> for child participant interviews) manage your/their condition? If so, how often do you use it/them?</child>
	How has your experience been of communicating with the health facility?
Challenges in the treatment process and	When were you (or <child name="" participant=""> for child participant interviews) first diagnosed? When did you/they start your first treatment?</child>
recommendation to support cancer care	Did you experience any difficulties with regards to care between the time you (or <child name="" participant=""> for child participant interviews) were first diagnosed and when you/they started to receive treatment?</child>
	Did you (or <child name="" participant=""> for child participant interviews) experience any difficulties in the admission process and/or referral process?</child>
	Did you experience any difficulties in collecting information related to your (or <child name="" participant=""> for child participant interviews) treatment?</child>
	Were there any aspects of your (or <child name="" participant=""> for child participant interviews) experience of cancer care that you feel could be improved to better support your/their needs?</child>
	Key: All items to be used with adult patient participants. For child participants, * indicates prioritizing obtaining the child participant perspective, + are items solely for child participants, and all remaining items can be explored with the caregiver of child participants whilst enabling and encouraging child participant involvement.

in the care of patients with cancer, health professionals and administrators involved in the management of cancer referral systems). A final framework will be agreed through discussion with the wider team. Once inconsistencies are resolved, all remaining interview transcripts will be coded within the joint coding frame. In order to explore common themes and divergences across the stakeholder groups, comparative analysis in the framework will be undertaken. A model of the coding frame will be developed, and each theme and subtheme defined to ensure the internal consistency of each code. Illustrative codes will be reported for each theme, with the study ID code to demonstrate reporting from across the sample breadth. Safeguards for rigour and quality of data analysis will be embedded into the analysis process, including regular team meetings to discuss transcripts, codes, and development

of themes, alongside verification of accuracy of data through listening to audio recordings of interviews and assessing transcripts by team members (AF, MJA). Where possible, respondent validation will be incorporated into the analysis, sharing summaries of preliminary findings with research participants to provide an opportunity for them to engage with, and add to, interview and interpret data. The final output from the analysis will be used to inform the development of conceptual maps, ensuring the representation of data from all participant groups.

Quantitative data. Descriptive statistics will be generated to inform specific themes of interest (as outlined in Table 7). Exploration of routine datasets will provide insights into the current distribution and demographic data of patients accessing

Table 7. The exploration themes for quantitative data analysis.

Data Source	Variables contained in dataset	Exploration Theme
Routine data held in medical records of participating hospital sites	Number of cases, age, gender, International Statistical Classification of Diseases and Related Health Problems 10th Revision (ICD-10) diagnosis, cancer stage, type of admission (emergency, inpatient, outpatient); referral status; outcome (discharged, died, referred, discharge against medical advice)	 Summary of the distribution and demographic data of cancer patients Utilization and access of cancer cases by hospital type
District health office records	Number of cases, age, gender, ICD-10 diagnosis, cancer stage	 Summary of the distribution and demographic data of cancer patients from the region Distribution and pattern of cancer prevalence by district health office in Yogyakarta region

cancer services in participating sites. This will also be explored at a regional level, with descriptive analysis of regional data providing insights into the distribution and patterns of cancer prevalence in the Yogyakarta region. Secondary data from routine reports will be analysed using Stata/MP 14.1 (StataCorp LLC, College Station, USA). We will also apply network representation analysis to visualise the data. Pairwise relationships between health facilities across the levels of the health system will be derived from descriptive analysis and will be described as a collection of nodes and edges to depict relationships between the facilities. This is intended to provide visually informative data alongside guiding conceptual model development as part of subsequent Theory of Change workshops.

Intervention development and modelling

This study intends to understand and map existing referral processes as part of cancer service provision in Yogyakarta. However, findings are also intended to be used to guide prioritization of future intervention development to refine existing referral processes. The findings from the quantitative and qualitative components of the study will be fed back to key stakeholders in cancer service delivery within Yogyakarta and national representatives. This will be used to elicit feedback on study findings and derive priorities for future research and intervention development.

A narrative synthesis approach will be used as a framework to guide the describing, comparing and combining of heterogeneous qualitative findings and quantitative results from across the study. The synthesis of findings will be used to generate conceptual maps. We will use elements of Popay *et al.*'s methodology of narrative synthesis⁵⁰ which guides the bringing together of disparate literature from multiple sources. We will follow the steps outlined by Popay *et al.*⁵⁰, which will include: i) developing a theory of how the referral system currently works, why and for whom; ii) developing a preliminary synthesis of findings from across the study activities; iii) exploring relationships in the data, including exploration of alignment of findings against the TOGAF approach (e.g. components of business, architecture, technology and data)

and eight interrelated dimensions of the socio-technical model; and; iv) assessing the robustness of the synthesis. Findings from qualitative and quantitative activities will be synthesised to guide the development of an underpinning theory of how referral systems currently work within Yogyakarta and generate conceptual maps for refinement through engagement with key stakeholders in the existing cancer referral system, including the Ministry of Health of the Republic of Indonesia, the Ministry of Information and Communication of the Republic of Indonesia, the Yogyakarta Special Region Health Office, the Association of Yogyakarta Special Region Hospitals, and BPJS as the national health coverage agency.

The use of a conceptual map (also referred to in the literature as logic models, analytical frameworks, concept maps, or influence diagrams) will provide a means of visualising the underlying theory of change beneath the existing referral system as determined through the study. The conceptual map presents a useful framework for describing how the referral system is believed to achieve its effects. By presenting this information graphically, rather than in narrative form, we hope to gain a clearer view of the relationship between constituent parts and how they interact. We will produce different types of conceptual maps for engagement with key stakeholders, including both activity maps (focusing on the implementation process and aiming to describe the intention of the referral system and the specific steps needed to achieve this intention) and outcomes maps (focusing on the connections between the resources, activities and the outcomes, which may be subdivided into short-term outcomes, long-term outcomes and impact). Discussions will also incorporate prioritisation of future efforts including around digital health technologies specifically for cancer, regulations that ensure the effectiveness and efficiency of cancer referrals (including financing, infrastructure, human resources, technology regulation, interoperability, and data standards), and potential partnerships between government and private sector (public-private mix).

Conceptual maps will be presented, reviewed, discussed and refined during stakeholder meetings and workshops. Two

workshops will be conducted. The first will focus on Yogyakarta stakeholders (District Health Office, Provincial Health Office, National Insurance Agencies, Indonesian Cancer Foundation, and health facilities) to determine pathways to impact at the provincial level. The second meeting will focus on the national perspective (with representatives from The Ministry of Health, Yogyakarta Provincial Health Office, National Insurance Agency, and Hospital Organizations) to discuss the recommendations derived from the research and their relevance for national policy. Alongside enhancing and validating findings from the study, conceptual maps will be used formatively as a mechanism for engaging with stakeholders and stimulating debate about the future development of the cancer referral system in Yogyakarta. The data collected will be the basis for interventions related to improvement and innovation for cancer referral services in Yogyakarta and may have national relevance.

Ethics

The study involves the participation of human subjects requiring consideration of ethics issues relating to informed consent of participants, beneficence, ensuring participant confidentiality and protection of study data, and a respect for privacy. This research has received ethical approval from the joint Medical and Health Research Ethics Committee (MHREC) of Universitas Gadjah Mada and Dr. Sardjito Hospital (No. KE/FK/1075/EC/209). The MHREC has the rights to monitor the research activities at any time.

Dissemination of information

A number of activities will be undertaken to support the dissemination of project findings. These will include: (1) developing newsletters and press releases to communicate key project findings to the general public, (2) delivering presentations at local and national conferences in Indonesia, alongside presentations at international conferences, (3) publishing articles in peer-reviewed journals and (4) social media through research team member and institutional accounts. Participants will

be anonymised in any dissemination activities. Only pseudonymised, non-identifiable characteristics and quotes will be used in dissemination.

Study status

The study is currently recruiting participants.

Research registration

This study has been registered with Research Registry (researchregistry 5807) 15/07/2020.

Conclusion

This research seeks to determine the current role of HIT in the provision of services and treatments for patients with cancer. Our findings will inform critical thinking around the design, implementation, adaptation, and evaluation of existing systems. Through early engagement and participation of key stakeholders and project partners, we intend the findings to have immediate utility. We will disseminate our findings to the Ministry of Health and other key stakeholders, alongside presenting findings at conferences and in peer-reviewed journals. Findings from the study will also be communicated to the government at regional and national levels, hospitals, and primary care centers as part of intervention development and modelling meetings. We will also develop a policy briefing report and an intervention guide related to improving cancer services in Indonesia based on the findings of this study.

Data availability Underlying data

No data are associated with this article

Reporting guidelines

Figshare: SRQR checklist for 'Protocol for a mixed-methods exploratory investigation of the role of health information technology in the provision of cancer care in Indonesia' https://doi.org/10.6084/m9.figshare.12656381.v1⁵¹

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Andree Kurniawan 🗓



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This protocol is fantastic and can be useful for cancer care in Indonesia. We will wait for the subject recruitment and study results.

My comment is about the sampling methods. How do you ensure that participant recruitment (healthcare provider and cancer patients) can represent the Indonesian population? Is there random sampling in several clusters? The second is about how do you gather data in qualitative methods, is there using focus group discussion or direct interview? The key person should be described to ensure the validity of the information.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Are sufficient details of the methods provided to allow replication by others?

Are the datasets clearly presented in a useable and accessible format?

Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Epidemiology, supportive care, cancer

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 29 Jun 2024

Matthew Allsop

Thank you for your time in reviewing the manuscript and for providing your comments. Please find below our response.

R2 comment: My comment is about the sampling methods. How do you ensure that participant recruitment (healthcare provider and cancer patients) can represent the Indonesian population? Is there random sampling in several clusters?

Authors' response: Thank you for your comment. We have proposed to undertake an exploratory study that begins to document and understand the types of systems being used for cancer care across the Yogyakarta region. This is a first step in developing the evidence base. We have developed sampling frames for all participant types but do not seek to have a sample that reflects the Indonesian population. For this exploratory work, we are seeking to obtain a wide range of views and perspectives from patients accessing cancer care and their health professionals across a range of settings to begin to understand current practice.

R2 comment: The second is about how do you gather data in qualitative methods, is there using focus group discussion or direct interview? The key person should be described to ensure the validity of the information.

Authors' response: Thank you. We will be conducting face-to-face interviews for the qualitative methods, either with individual adult participants or with their caregivers present. We will also undertake face-to-face interviews with child participants with their caregivers present.

Competing Interests: No competing interests were disclosed.

Reviewer Report 02 June 2021

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I think this subject is very interesting and can be helpful for health information technology experts.

- In table 1 what is medical subspecialty?
- In table 2 the total column is referring to organization number or patient number?
- In article said there is 10 organization but selected 9, what is the reason to choose 9? (Table 2 and figure 1).
- In table 2 in total column 306 and selected 2 in the next column. Honestly I cannot understand why 2 from 306 selected? Or these columns are not related to each other.
 Please explain more about table 2.
- What is the method for sampling patient in figure 1?
- In figure 1 about hospital staff, what is the sampling method? And how many people are selected in each position?
- In table 3: number of health facilities is more than 10?
- on page 9 in second paragraph after reference of 49, you write "dyads". What is it?
- In table 6: which of these question asked of children and which of them asked about adults?
- Conclusion is very short. I suggest explain more for example about limitation of study, compare result with same studies.

Is the rationale for, and objectives of, the study clearly described?

Yes

Is the study design appropriate for the research question?

Yes

Are sufficient details of the methods provided to allow replication by others?

Partly

Are the datasets clearly presented in a useable and accessible format?

Partly

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Health information management and health informatics.

I confirm that I have read this submission and believe that I have an appropriate level of

expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 29 Jun 2024

Matthew Allsop

R1 comment: I think this subject is very interesting and can be helpful for health information technology experts.

Author response: Thank you for your comments and for your guidance on improving our manuscript.

R1 comment: In table 1 - what is medical subspecialty?

Author response: Thank you for your comment. This was a repetition of information in the table that has now been removed. We describe basic medical speciality and supporting medical speciality categories in the footnote of the table.

R1 comment: In table 2 - the total column is referring to organization number or patient number?

Author response: The total column refers to the total number of facilities of that type in the Yogyakarta region. We have now clarified this in the column title.

R1 comment: In article said there is 10 organization but selected 9, what is the reason to choose 9? (Table 2 and figure 1).

Author response: Thank you for highlighting this. We have amended the word "ten" to "nine" to align with the plans detailed in the table and figures.

R1 comment: In table 2 - in total column 306 and selected 2 in the next column. Honestly, I cannot understand why 2 from 306 selected? Or these columns are not related to each other. Please explain more about table 2.

Author response: This is correct that we seek to recruit two primary care sites, as detailed in the table. This work is an exploratory study to address gaps in the evidence base. While it may have been helpful to sample a higher number of primary care sites, this is not possible within the confines of the budget available for this study. We have reflected this limitation in the section outlining the methodology relating to health professional interviews.

R1 comment: What is the method for sampling patient in figure 1?

Author response: We have addressed this omission in our reporting of methods through adding the following text to the Sample Selection section: The research team will liaise with the Head or Director of Patient Services at each facility to support the identification of eligible health professionals. The research will liaise with clinical staff supporting patients with cancer to identify and support the recruitment of patient participants.

R1 comment: In figure 1 about hospital staff, what is the sampling method? And how many people are selected in each position?

Author response: As part of our response to the prior comment, we have also added details of the sampling method for hospital staff. We will remain flexible around the recruitment across different positions based on availability and willingness to participate across the facilities. We have not provided specific expectations of figures across each position but do specify that we will seek to recruit participants across all positions.

R1 comment: In table 3: number of health facilities is more than 10?

Author response: Thank you. The figures represent the number of health facilities that have the cancer service type available. For example, 3 of the cancer services have one-day care services, from which we will sample 4 patients at each. This will result in up to 12 participants being recruited across these services.

R1 comment: On page 9 in second paragraph after reference of 49, you write "dyads". What is it?

Author response: Dyad referred to interviewing two participants together to collect data, but we have clarified this in the text to now read "As such we will be flexible about whether interviews are conducted with individual patients or with their caregivers present".

R1 comment: In table 6: which of these question asked of children and which of them asked about adults?

Author response: We have clarified in the topic guide which questions are solely for child participants and which are for exploring primarily with caregivers of child participants, but with child participant input encouraged. We have also provided flexibility with the way in which questions can be posed based on the participant type.

R1 comment: Conclusion is very short. I suggest explain more for example about limitation of study, compare result with same studies.

Author response: Thank you. We have now reflected limitations in responding to prior points raised. In terms of the conclusion, given this is a protocol we do not yet have results to compare to the literature. After we have conducted the research, we will be able to contextualise our findings within existing literature. We have however included an introduction section that provides an overview of the state of evidence to date and the need for the research.

Competing Interests: No competing interests were disclosed.

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