The impact of informal patient navigation initiatives on patient empowerment and National Health Insurance responsiveness in Indonesia

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ABSTRACT

Background Indonesia introduced a universal National Health Insurance (NHI) programme *Jaminan Kesehatan Nasional* (JKN) in 2014. However, challenges in timely consultation and access to health services resulted in the introduction of formal and informal patient navigation initiatives which facilitates access for patients. Informal patient navigation may emerge from the gaps in the services of the formal patient navigation. This study assesses how three *informal* non-government patient navigation initiatives emerged, are organised, operate and interact with JKN authorities to enhance patient empowerment and JKN responsiveness.

Methods This was a qualitative study comprising of document review, semi-structured interviews with key stakeholders and direct observations at JKN-contracted health facilities. Data was analysed deductively and inductively using Molyneux *et al*'s accountability assessment framework to assess context, content, and process of the informal patient navigation initiatives.

Results Our study found that informal patient navigation initiatives bridge a gap left by formal navigation initiatives. The navigators help spread awareness among patients of their benefits and entitlements and assist patients to communicate with health providers and authorities. However, we find limited effects on people's ability to navigate the system themselves, on systemic change, or on JKN responsiveness.

Conclusion We may know that when access to health services is challenged then formal or informal patient navigation initiatives to facilitate access for patients may emerge. What this study adds is how informal patient navigation bridge a gap left by formal navigation initiatives, from how they are organized, operate and interact with the NHI authorities. We demonstrate that in the absence of well-functioning formal navigation initiatives, the informal initiatives may fill a critical gap. However, their efforts are time intensive and do not translate across the population. What is implied here is that more is required from JKN authorities to enhance interaction with informal patient navigation to advance systemic change toward equitable access to NHI.

WHAT IS ALREADY KNOWN ON THIS TOPIC
⇒ Patient navigators are often part of the formal health service delivery structure and play an important role in facilitating access to healthcare especially for vulnerable patients and those with catastrophic illness.

WHAT THIS STUDY ADDS
⇒ This study adds insights on the emergence and significant role of informal patient navigation initiatives in Indonesia.
⇒ The process of engagement, empowerment and advocacy for individuals varies across navigators providing positive but equally varied results, and limited systemic change.

HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE AND/OR POLICY
⇒ Research on other informal navigators in Indonesia (those not rooted in labour activism) would complement this study with implications for Jaminan Kesehatan Nasional (JKN) authorities as well as patient support.
⇒ Structured mechanisms of interaction between JKN authorities and informal patient navigation initiatives are needed in order to enhance synergy and efficiency for patient support.
⇒ Collaboration between informal patient navigation initiatives would strengthen their influence over the JKN authorities.

INTRODUCTION
As per the latest data from the WHO Universal Health Coverage (UHC) 2021 Global Monitoring Report and in common with many other low-income and middle-income countries, Indonesia improved on the health service coverage index from 45% in 2010 to 59% in 2019.[1] However, improvements in financial protection have not been commensurate. Household out-of-pocket expenditure as a share of current health expenditure in Indonesia was 32% in 2018,[2] which is higher than the average for the East Asia and Pacific

region (26.19%).[3] In 2019, around 5% of the households faced catastrophic health expenditures (measured as out-of-pocket expenditures above 10% of household consumption or expenditure).

In order to move towards UHC, Indonesia launched a health insurance programme—*Jaminan Kesehatan Nasional* (JKN)—in 2014 with the aim to provide access to quality health services for all. JKN is funded through members' contributions as well as general government revenues to subsidise low-income and vulnerable households unable to make contributions. JKN is managed by *Badan Penyelenggara Jaminan Sosial Kesehatan* (BPJS) which reported that JKN covered 86% of the population (approximately 235 million members) by December 2021, of which 85 million were subsidised members (approximately 36% of the total).[4]

Despite this, studies reveal persistent problems:

▶ *Unequal access for subsidised members* compared with contributing members.[5] This is due to differential treatment by hospitals claiming that JKN's case-based payment rates for subsidised members, which are lower than those for contributory members, do not sufficiently cover the cost of treatment.[6–9]

▶ *Patient confusion about their entitlements* due to frequent changes in JKN regulations.

▶ *Uneven availability of health facilities* across Indonesia especially outside of Java island.[10]

Several of these challenges can be addressed through patient navigation support which emerged to promote equitable access to timely consultation and treatment by eliminating barriers to care.[11] The poor, patients with multiple morbidities and those with long-term, often terminal illness such as cancer, have been shown to benefit from navigator support.[12–14] A scoping review of multiple studies showed that patient navigation initiatives improve access to health services through providing patients with individualised assistance, health education and support and communicating with multiple agencies.[15] Patient navigation aims at improving outcomes for a variety of health services.[16]

Recognising the role of patient navigation, and in order to comply with Public Service Law 25/2009 requiring all public service providers to improve service delivery and accountability, the Indonesian government established four initiatives to assist JKN members in accessing JKN benefits:

1. 'Lapor.go.id': is a web-based grievance collection mechanism that was established in 2013 and can be used by citizens to report on the quality of all public services, to submit issues and request solutions. JKN was included in this list of services.

2. 'Care Center 1-500-400': is a 24/7 phone-based hotline service managed by BPJS Kesehatan. It responds to patient queries and forwards patient grievances to BPJS Kesehatan for follow-up.

3. 'Mobile JKN': is a smartphone based application which provides information, for example, on membership status, location of health providers, availabil-

ity of free beds and schedules of doctors and surgery options.

4. 'BPJS Satu': consists of having designated BPJS employees assigned to selected hospitals to provide (face-to-face) navigation assistance to JKN members and to address patients' grievances about JKN.

The Care Center, Mobile JKN and the BPJS Satu were introduced by the government specifically to provide navigation support to patients, and therefore referred to as 'formal'. Suboptimal performance and people's discontent with these formal patient navigation initiatives have led to the emergence of various informal, that is, non-governmental navigation initiatives operating in parallel. Berenschot *et al*[17 18] have described informal support mechanisms as (individual) brokers in a patron–client relationship. In contrast to these, we have identified various group-based, voluntary informal navigation initiatives that do not reinforce patron–client relationships. Yet little is known about the emergence and operation of these latter initiatives and their interaction with JKN authorities.

In order to close this knowledge gap, we focus on three such informal initiatives that to our knowledge are the largest and most known ones—BPJS Watch (*Badan Penyelenggara Jaminan Sosial Watch*), Jamkeswatch (*Jaminan Kesehatan Watch*) and POSKO JKN-KIS (*Pos Komando Jaminan Kesehatan Nasional – Kartu Indonesia Sehat*). We explored the following research questions:

▶ Emergence: How and why did these three informal navigation initiatives emerge?

▶ Organisation: How are these informal navigation initiatives organised?

▶ Operation: How do they operate to improve access to healthcare services?

▶ Interaction: How do they interact with formal government patient navigation initiatives?

▶ Outcomes: Do they empower patients and increase the responsiveness of JKN, and how?

The objective of the paper is to understand whether and how informal patient navigation initiatives in Indonesia empower patients and lead to more responsive health insurance as important intermediate elements to progress towards UHC. Such understanding is relevant to countries with emerging National Health Insurance (NHI) schemes and under-resourced health systems.

METHODS

Conceptual framework

To analyse Indonesia's informal patient navigation initiatives, this study uses Molyneux *et al*'s accountability assessment framework,[19] which suggests exploring the 'context', 'content' and 'process' of accountability initiatives to understand their functioning and their effectiveness. In our study, 'context' refers to the broader social and economic factors that shape how the informal initiatives emerged; the 'content' refers to how the informal navigation initiatives are organised; and the 'process'
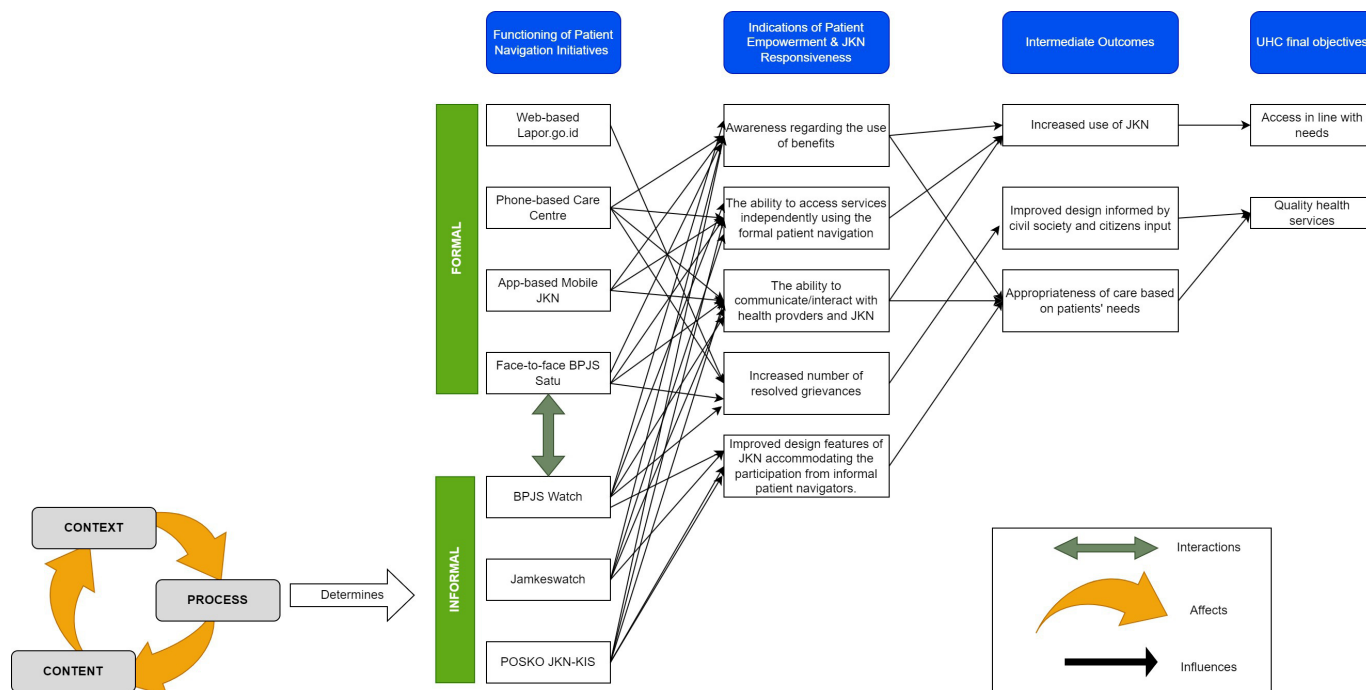
Figure 1 Potential effects of the patient navigation initiatives on patient empowerment and JKN responsiveness, outcomes and UHC objectives. app, application; BPJS, *Badan Penyelenggara Jaminan Sosial;* Jamkeswatch, *Jaminan Kesehatan Watch;* JKN, *Jaminan Kesehatan Nasional*; POSKO JKN-KIS, *Pos Komando Jaminan Kesehatan Nasional – Kartu Indonesia Sehat;* UHC, universal health coverage

is understood in terms of how they operate in practice. We consider an additional dimension that explores how these informal navigation initiatives interact with JKN authorities.

The contribution of navigation initiatives to UHC is not linear nor direct. Figure 1 provides a simplified logic model indicating how formal initiatives as well as informal patient navigation initiatives in Indonesia could enhance empowerment of members and responsiveness of the JKN programme and how this could affect intermediate outcomes as well as progress towards UHC. The logic model is adapted to incorporate Molyneux *et al*'s framework as described above.

Data collection and analysis

Exploring different perspectives of stakeholders with varied experiences about JKN implementation was critical to achieve study objectives. The study design was therefore qualitative in nature comprising three sources of data: (1) government documents and existing literature, (2) semi-structured interviews and (3) direct observation at health facilities.

Location selection

We purposively sampled districts to examine coverage by different informal navigation initiatives and to also capture variation in access to healthcare. The latter aspect is important in view of the inequities in access between rural and urban areas, and also between Java and other islands.[20] We selected eight districts in four provinces: South Jakarta, West Jakarta, Central Jakarta and East Jakarta in Jakarta province (megapolitan area), Bekasi and Karawang in West Java province (industrial zones), Mojokerto in East Java province (suburbs and rural) and Manado in North Sulawesi. BPJS Watch and Jamkeswatch report operating in all sample areas, while POSKO JKN-KIS operates in Bekasi and Karawang (see figure 2).

Document analysis

We initially examined four official reports on JKN implementation issued by BPJS Kesehatan, Dewan Jaminan Sosial Nasional (DJSN, National Social Security Council) and the Ministry of Health. We also reviewed 19 peer-reviewed national and international publications on UHC tracking for the period from 2014 (the start of JKN) to 2021. We used these to understand the institutional context of JKN, utilisation of health services covered by JKN, the history of informal patient navigation and the regulations affecting access to JKN benefits.

Semi-structured interviews

Data collection was carried out during the following times: Jakarta, Karawang and Bekasi (4 January–28 February 2020), Karawang (26–30 January 2021), Mojokerto (6–8 February 2021) and Manado (4–8 April 2021). We started with Jakarta, Karawang and Bekasi given the proximity of location to the researchers that allowed us to collect data during the COVID-19-related mobility restriction policy. The next round was done in 2021 after the country had passed the first and second waves of the pandemic, thus allowing researchers to travel to Karawang, Mojokerto and Manado.

Sample area :
Jakarta, Karawang, Bekasi,
Mojokerto & Manado

Figure 2 Map of Indonesia and location of research.

We selected four types of respondents through the following sampling methods:

1. *Navigators from the three informal navigation initiatives*: 28 volunteer navigators were identified based on the researchers' contacts with labour activists in the sampled areas including individuals in leadership positions. For POSKO JKN-KIS, we interviewed only two individuals due to COVID-19 mobility restrictions.

2. *Patients*: Due to mobility restrictions during the COVID-19 pandemic, the research team used a combination of purposive and snowball sampling. Inclusion criteria required patients to be poor or near-poor and work as non-salaried workers, seasonal workers or farmers. Thirteen patients were identified by navigators while the other five patients were identified through the researchers' social networks.

3. *Health professionals:* We had initially envisaged purposively sampling health professionals in each district but due to the COVID-19 pandemic, we interviewed only nine health professionals in two districts (seven from Jakarta and two from Manado). These included members of the hospital association, the nurses' association, public and private hospital doctors and public health practitioners. They were identified through JKN authorities or through their frequent contributions to JKN issues in the media.

4. *JKN authorities from various government agencies at national level:* These were identified through the researchers' networks. Out of the 18 persons invited, 15 were interviewed.

Guiding interview questions were prepared for each respondent type. These were pilot tested with JKN members not included in the study (two labour activists, male and female; and one male layperson) and further improved. We did not test the interview questions to JKN authorities and health professionals because the

sampling number of these informants are relatively small and they were difficult to contact.

Respondents were contacted in different ways: JKN authorities were sent a formal letter via email; navigators and patients were invited via the commonly accepted WhatsApp mobile application. All those invited were provided with consent forms using the same media. Study details including the purpose of the study, voluntary and anonymous participation was explained prior to requesting verbal consent. All those invited, except three government representatives, accepted the invitation and made themselves available for the interviews.

Interviews were done by a group of two or three researchers (DPR, FSJ, RH) and lasted between 60 and 90 min each. All interviews were audio-recorded and transcribed verbatim. Field notes after every interview were collected and discussed thoroughly for the analysis. All respondents provided verbal consent, with half meeting in-person and the other half being interviewed via video calls.

A summary of the total number and types of respondents as well as interview topics can be found in table 1.

Three researchers (DPR, RH and FSJ) read the transcripts and coded the data using a combination approach: deductive codes were extracted from the main themes in the interview guides (context, content, process, interaction, outcomes); within these categories, inductive codes were developed as result of the specific themes emerging from the various interviews. Differences in coding were resolved through consensus.

Direct observations

We visited five district-level community health centres, seven public hospitals and three private hospitals in eight districts across four provinces. We observed the presence and practices of BPJS Satu Officers' as well as those of

Table 1 Summary of the number and types of respondents

Informant category and gender break down	Affiliation details and numbers	Interview topics:
JKN authorities at national level N=15 (5 females, 10 males)	BPJS Kesehatan: 7 National Social Security Council (DJSN): 3 Ministry of Health: 1 Founder of *Lapor.go.id:* 1 Ministry of State Apparatus Empowerment and Bureaucratic Reform: 3	▶ Implementation of the formal patient navigation initiatives and related challenges. ▶ Perception of JKN authorities toward informal patient navigators. ▶ Motivation to engage with informal patient navigators. ▶ Modes of interaction between JKN authorities and informal patient navigators. ▶ JKN authorities' responses to informal patient navigators input on JKN design and processes.
Navigators from BPJS Watch, Jamkeswatch and POSKO JKN-KIS N=28 (1 female, 27 male)	BPJS Watch in Jakarta: 3 BPJS Watch-associate in Manado: 5 POSKO JKN-KIS in Bekasi: 2 Jamkeswatch Jakarta: 1 Bekasi: 3 Karawang: 2 Mojokerto: 10 Manado: 1 Pasuruan: 1	▶ Profile of informal patient navigators. ▶ The factors shaping the emergence of informal patient navigators. ▶ Services of informal patient navigators. ▶ Motivation of informal patient navigators for providing and maintaining services. ▶ Problems for patients and informal navigators in using formal patient navigation initiatives. ▶ Modes of interaction between informal patient navigators and JKN authorities. ▶ The extent to which informal patient navigator assistance increases patients' abilities to access JKN services independently.
Health professionals N=9 (2 female, 7 male)	Jakarta: 7 Manado: 2	▶ Perception of health professionals on JKN implementation. ▶ Modes of interaction between health professionals and informal patient navigators at health facilities.
Patients availing JKN benefits N=18 (7 female, 11 male)	Jakarta: 4 Karawang: 2 Bekasi: 2 Mojokerto: 7 Manado: 3	▶ Patients' knowledge and awareness about the existence of informal patient navigations. ▶ Issues affecting access to JKN services. ▶ Patients' experiences in using formal and informal patient navigation. ▶ The extent to which informal patient navigator assistance. increases patients' abilities to access JKN services independently.

BPJS, *Badan Penyelenggara Jaminan Sosial*; Jamkeswatch, *Jaminan Kesehatan Watch*; JKN, *Jaminan Kesehatan Nasional*; POSKO JKN-KIS, *Pos Komando Jaminan Kesehatan Nasional – Kartu Indonesia Sehat*.

the informal navigators. The first three authors carried out the observations based on prior briefing and documented their field notes which were discussed during the analysis process. Observations were halted on data saturation.

Data validation
Researchers discussed all aspects of the data obtained through interviews, observation and document analysis. In addition to triangulation using the various sources described above, we sought to validate the data through member checking: we organised two rounds of online meetings with informants in June and August 2021. The purpose of these meetings was to share our preliminary findings and invite feedback. Any misperceptions or inaccuracies were subsequently addressed.

FINDINGS
We begin with an examination of how and why the three informal navigation initiatives emerged in Indonesia (the context). Scrutinising the data and searching for similarities and differences, we then analyse how they are organised (content) and how they operate, that is, contribute to improving access to health services (process). We also explore the interaction between the informal patient navigators and JKN authorities. We weave any evidence of patient empowerment and JKN responsiveness (or lack thereof) as outcomes across all sections where relevant.

How and why did the informal navigation initiatives emerge ('context')?
The intertwined history of labour activism and social security in Indonesia
The historical role of labour activists in the development of JKN was an important factor behind the emergence of the informal navigation initiatives.[21] Our interviews confirmed the findings from previous studies on how labour union activism led to the development of a coalition that pushed for the enactment of social security laws.

The connection of labour activists with JKN started with KAJS (*Komite Aksi Jaminan Sosial* the Action Committee for Social Security), comprising over 60 trade union and civil society activists and academics. KAJS advocated

for the government to institute a specific BPJS law to ensure the implementation of health insurance under the umbrella of the broader National Social Security Law No. 40 that had been passed in 2004.[22] When this BPJS specific law was passed in 2011, KAJS transformed into a new network called BPJS Watch which consisted of activists advocating for the actual implementation of social security programmes, including JKN.

Following the launch of JKN which began in January 2014, two other initiatives emerged. In September 2014, KSPI (*Konfederasi Serikat Pekerja Indonesia*) as the second largest confederation of workers in Indonesia split from BPJS Watch and declared the founding of Jamkeswatch which started monitoring JKN operations in Bekasi and Surabaya and then in other parts of Indonesia.[23] Another group called POSKO JKN-KIS, comprising of labour activists from various trade unions was established in May 2017, operating in the industrial zones of Bekasi and Karawang.

Fuelled by cases of rejections of JKN members from accessing hospital benefits, the activists transformed their advocacy activities into informally operating patient navigation initiatives. Their motive was to provide real-time solutions to address JKN member rights violations and overcome access challenges.

Poor design of formal navigation initiatives

Another catalyst for the emergence of informal initiatives was the poor design of formal navigation initiatives that add to structural barriers to access. Patients reported about the long waiting times on the phone for the Care Center that subsequently translated into unaffordable local phone call charges especially for those using prepaid calling cards. Respondents noted that the Mobile JKN application fails to provide easy-to-find information about membership status and that the application does not provide information about fines resulting from late contribution payments or the poor being dropped from government subsidy:

> When my father […] was sick and brought to the hospital at midnight, the hospital rejected us saying that we still have unpaid JKN contribution. I said[…] I would pay the next morning but still we were rejected. So we returned the next morning only to find out that the payment was still not processed by BPJS Kesehatan. We later found out that the late payment has incurred a fine…. I was so frustrated because I could not find information about this on Mobile JKN. (*Patient, Informant #34, Jakarta*).

> For Mobile JKN, we cannot do anything for the poor whose status is non-activated by the government…like last year, (2019) people only know that they are dropped from the subsidy once they need health treatment. (*BPJS Satu, Informant #30, Jakarta*)

Finally, information provision through a mobile application is of limited use to those without a smartphone, beneficiaries with unreliable internet, or individuals with limited digital literacy:

> For Mobile JKN, not all members know how to use or download it. Most people would prefer seeing or talking to someone about their [JKN] issues. (*BPJS Satu, Informant #26, Jakarta*)

Inadequate information about the formal initiatives and their poor performance

We found that JKN members did not have sufficient knowledge about JKN in general including about the formal patient navigation initiatives. For instance, many patients were not aware of BPJS Satu officers and reported that they had rarely seen signs or posters about the BPJS Satu services in the hospitals that they visited. One navigator stated:

> There may be BPJS Satu officers, but they don't exist in all hospitals and they are limited in numbers. (*Navigator Informant #30, Mojokerto*)

The insufficient knowledge of JKN members to navigate formal patient navigation initiatives strengthened the desire of the labour activists to offer their own services to their colleagues and to communities.

According to the informal navigators, patients who did use the formal navigation initiatives cited poor performance of these initiatives. These included processes and regulations that impeded the ability of those working in formal navigation initiatives to promptly respond to patient's needs. The quotes below illustrate some of these challenges:

> The operator [Care Centre staff] does not fully understand JKN. For my case, the operator still needed to contact the person-in-charge at BPJS Kesehatan before making a decision to help us. Such chain of procedure lengthens the process to solve our problems. (*Navigator Informant #24, West Java*)

> If we contact the Care Center, the patient may die already. Die because the response is not prompt enough. (*Navigator Informant #19, Jakarta*)

How are the informal navigation initiatives organised ('content')?
Similarities in objectives, ethos and informality

All three informal initiatives have the objective to assist the poor and the vulnerable to access JKN benefits by: (1) providing information and practical guidance on how to avail JKN benefits, including when patients experience administrative hurdles, (2) offering navigation assistance through accompanying the patient or patient's family while accessing care and (3) advocating with health centres and JKN authorities for design and/or implementation adjustments that will relieve access barriers for the poor. Jamkeswatch, in particular, also pressures JKN authorities through demonstrations and media campaigns, and sanctions hospitals that do not provide benefits as per the legal provisions.

All three are comprised of loose groups of concerned citizens, who work as volunteers without a formal structure, salary or compensation. They mobilise support

among volunteers to help with knowledge building or donating money for transportation. Regarding their motivation, interviews with navigators revealed that they wanted to ensure that health facilities provided JKN members with high quality of care and that they did not discriminate against those who are unable to pay user fees. This was underpinned by the historical responsibility as labour union activists to ensure that JKN implementation is aligned with UHC and social justice objectives, and a sense of compassion for the poor and vulnerable to be treated fairly. This is therefore not a career for them but something they do voluntarily without any remuneration. This altruistic attitude differentiates the navigators in this paper from the individual, clientelist brokerage model described in the work of Berenschot et al.[17 18]

Initially, in order to train volunteers on the specifics of JKN, all three navigation initiatives had provided basic reading materials to their navigators. BPJS Watch and Jamkeswatch had produced a handbook for their navigators in 2014, but it was never reprinted or revised given constantly changing JKN rules and variations in how rules have been implemented across areas. Thus, volunteers now rely on informal information provision through WhatsApp groups, café talks and internal discussions among peers to upgrade their knowledge and skills in providing support. Only Jamkeswatch leaders are trained at their headquarters in Jakarta. While BPJS Watch does not have training schedules for their navigators, the navigators can ask leaders about JKN rules and guidance on how to assist beneficiaries to navigate the JKN system. It is thus important to note therefore that none of the three informal initiatives have institutionalised procedures for assisting patients. Further, volunteers lack any health-related training. This might constitute a barrier both in terms of how they are perceived by the formal health system, influencing the nature of the communication and the relationships between these actors, as well as to their ability to provide beneficiaries practical advice around receipt of healthcare services.

Differences in organisational structure, size and operations

The three initiatives do, however, differ in their governance and organisation. This in turn affects how they function and the extent of their outreach.

BPJS Watch operates solely in Jakarta and its reputation spreads by word of mouth. Unlike the other two initiatives, it does not have any legal status as an organisation, has no established office and has no identity cards for its navigators.

Jamkeswatch covers a total of 40 districts in 17 provinces across the country with each branch having a designated leader from among the navigators. It has approximately 1000 volunteers, most of whom have identity cards, even though these are not always needed as hospital staff are already familiar with the navigators. Navigators work in pairs with one attending to the patient while the other meets with hospital authorities.

POSKO JKN-KIS consists of volunteers from various labour confederations (KAJS, KSPSI (Konfederasi Serikat Pekerja Seluruh Indonesia), KSPI), as well as local solidarity groups such as PPMI (the Brotherhood of Indonesian Muslim Workers) and PSM (Social Workers Group in Bekasi). Some navigators are non-labour activists such as community leaders, former civil servants, retired military personnel and seasonal workers. Although they are unable to specify the exact number of navigators, their WhatsApp group comprises of approximately 245 members. Most navigators carry POSKO JKN-KIS identity cards when assisting patients. To improve their standing with JKN authorities POSKO JKN-KIS established a memorandum of understanding with BPJS Kesehatan and the local government in West Java.

The navigators use WhatsApp groups to share information with other navigators on the availability of health facilities, the person to contact at the local health facility or local BPJS Kesehatan office and the proposed approach suitable to help the patients in accordance with JKN rules and procedures. POSKO JKN-KIS maintains two different forums via WhatsApp groups: one for navigators only and another one for the navigator leaders and JKN and healthcare authorities, whereas Jamkeswatch maintains a WhatsApp group for all its navigators in the area of operation. BPJS Watch navigators usually do not use WhatsApp groups to inform other navigators of their decided course of action; they individually determine the best course of action.

How do the informal navigation initiatives operate to improve access to healthcare services ('process')?
Process of assisting patients

Navigators in all three initiatives are typically approached informally by patients based on recommendations from former patients, peers or neighbours or labour activists. Patients we interviewed had usually interacted with only one of the three informal navigation initiatives. While there is generally little overlap between the three initiatives that tend to work independently when supporting patients, there are opportunities for collaboration given that some of the leaders know each other personally due to their shared roots in labour movements.

Navigators are usually contacted approximately four to six times a month via phone or WhatsApp by patients or family members needing navigation assistance. The navigator first assesses the patients' needs, for example, need for intensive care, or for administrative support to verify or activate JKN membership. Typically, navigators would at this time ask for the patients' JKN number, the illness and problems at hand and then also check the JKN membership status of the patients, either by calling the BPJS Kesehatan branch office or via the Mobile JKN application. Checking the membership status is important to determine how best to assist patients. They also liaise with the patients' family in order to track steps previously taken by patient in navigating the JKN administrative process. Thereafter, the navigator would typically discuss the case

in the relevant WhatsApp group. The navigators then give information to the patients or family members on the next steps needed by the patients to access benefits.

Types of support provided

Interviews with patients revealed that navigators often assist with arranging transportation to a hospital. Where needed the navigators consult a physician within the navigators' network (in their WhatsApp group) to provide medical advice or intervene with the facilities. In cases where hospitals reject admission of a JKN member, navigators accompany patients to negotiate with them. Navigators also indicated that they sometimes made spot visits to hospitals to identify empty beds, thereby ensuring that facilities could not report being full as a pretext to reject JKN patients, particularly those belonging to the subsidised group.

Navigators also help ensure that JKN members are not charged for medicines, laboratory tests or blood transfusions when they are discharged from hospitals—a malpractice that frequently occurs. Jamkeswatch claims that their advocacy has assisted in uncovering such violations and having them addressed, with hospitals being obligated to return such out-of-pocket payments to patients. Navigators also often field requests from poor patients who were not members of JKN. In such cases, the navigators would help eligible individuals enrol through the local government subsidy programme, which is usually a faster option to get enrolled than waiting for the admission process by the central government. Navigators also use personal connections with hospital directors, branch officers of BPJS Kesehatan, mayors or head of districts to increase the likelihood of having a patient admitted.

The navigators also do not hesitate to escalate issues to the BPJS Kesehatan Board of Directors at the national level, the mayor or the district head, especially in cases where a patient requires intensive care, which is severely limited in Indonesia. However, negotiation with facilities and prior investigation are the preferred tactics to immediate escalation, as expressed here:

> Typically […], we try not to be too argumentative because we need to maintain (a) good relationship with the hospital. (*Navigator, Jamkeswatch Informant #48, Bekasi*)

Informality in the navigators' assistance processes and their limitations

The informal nature of these three navigation initiatives also manifests in the documentation of cases. In the early years of operation of these initiatives, navigators attempted to document cases, but they lacked the human resources and funding to do this systematically. Navigators therefore share details of each case through WhatsApp, but there is no central filing of these. POSKO JKN-KIS has created a format for reporting cases on their WhatsApp group, but records of these are not retained.

The informality of navigators' assistance has its advantages as well as challenges. Advantages for patients include being able to approach navigators anytime and receive real-time assistance based on need and circumstance. However, navigators realise that they may not be able to help patients overcome all barriers to JKN access such as finding a bed in an already full hospital or ensuring members receive appropriate care based on need. Further, navigators worry about patient dependence, believing that only a handful of the patients they assist can transform their experiences into accessing JKN benefits independently for future health utilisation. The patient interviews confirm this:

> I won't know the way. I'm afraid of making mistakes, it's too complicated. (*Patient, Informant #18, Bekasi*)

> I don't have the courage….the hospital may ask things that I cannot answer. I am only a junior high school dropout; I am nervous that I'd make mistakes. (*Patient, Informant #37, Mojokerto*)

The testimony from patients suggests that the existing patient navigation initiatives as they are currently designed and implemented have only a limited impact in empowering members to accessing JKN benefits independently.

How do the informal navigators and JKN authorities interact?
Communication and the importance of formal and informal exchanges

Given the shortages of health facilities, tight JKN reimbursement rates to hospitals, and the importance of constructive engagement, informal navigators prefer to find cooperative ways to find a solution with health providers in line with JKN rules rather than reporting them to higher authorities. Similarly, all the health professionals we interviewed noted that hospitals are particularly aware of the influence of informal navigators on the public, thereby making doctors to cooperate with them as illustrated here:

> Yes, I am aware of those calling in to get help on certain patients. I'd rather be responsive to them; or else the management would be approached by those navigators and then the management would bother me anyway with the same request. (*Doctor, Informant #54, Manado*)

As watch dogs, the navigator initiatives believe that they should be independent from the government and BPJS Kesehatan. For example, BPJS Watch has a strict policy against volunteers receiving funding or payment from BPJS Kesehatan. This independence, for instance, also confers legitimacy for convening regional forums on JKN topics such as the ones organised by POSKO JKN-KIS where government and non-government stakeholders meet to discuss, share and consult on JKN issues.

All interviewed navigators reported that they maintained informal communications with the BPJS Satu formal navigation initiative, hospital managers and BPJS Kesehatan branch officers. For instance, BPJS Watch navigators exchange WhatsApp messages with these authorities around JKN implementation challenges. They also

organise ad-hoc meetings with local JKN authorities and local politicians who have a particular interest in JKN.

Public advocacy and the use of media

All three navigation initiatives, and the value of their experiences, are generally well known to JKN authorities. Their activities are often showcased in the media and their leaders are invited by JKN authorities to provide input—in private exchanges as well as publicly—to BPJS Kesehatan, DJSN and/or Ministry of Health discussions.

The BPJS Watch leadership in Jakarta often produces critical commentaries on JKN regulations and their implementation and shares these with the public through WhatsApp messages, television and radio talk-shows or by organising press conferences. There have been several occasions when Jamkeswatch has mobilised labour activists to hold demonstrations in front of BPJS Kesehatan or the Ministry of Health office to demand better JKN design and implementation. Jamkeswatch also shares its observations on JKN in its blog called 'Koranperdjoeangan.com'. It is therefore known among JKN authorities as 'the fierce advocate' for patients accessing JKN benefits in Bekasi and Mojokerto.

Overall positive relationships coupled with caution on both sides

All the respondents from JKN as well as navigators expressed that interactions among them were positive. JKN authorities at different levels indicated that navigators were well-informed about rules and regulations and that they maintained frequent and friendly communication. BPJS Kesehatan officials that we interviewed highlighted BPJS Watch's 'outstanding literacy' in JKN regulations as well as their persuasion style. As one respondent noted:

> The key person involved in BPJS Watch shares his op-eds [a piece on the opinions and editorials page] regularly through WhatsApp with me. That's how we are updated of what they are up to, and we see that he always uses data to prove his point. (*BPJS Kesehatan, Informant #3, Jakarta*)

Managers and admission staff at hospitals are often seen as reluctant to implement JKN regulations. Navigators mentioned that hospitals are more driven by reimbursement motives than by patient considerations. By contrast, health professionals admit that interactions with informal navigators can be challenging due to their lack of medical knowledge which often leads to heated debates between the two sides.

> We [hospital] are in a difficult position. The navigators blame us if we don't respond as they wish, because we have to take into account the condition of the patient. Doctors also must consider which item of treatment can be reimbursed by BPJS Kesehatan…We feel under pressure when we receive such baseless accusations [from navigators]. (*Doctor, Informant #33, Jakarta*)

Our interviews revealed varied perspectives between patient navigators and JKN authorities on the functioning of JKN. JKN authorities note that they are cautious in their interactions with the informal navigator groups for fear of being perceived as providing preferential treatment:

> We have to be very careful in facilitating meetings with NGOs. Now there are BPJS Watch, Jamkeswatch and others. We must be careful (in) how to choose between them. If they send a formal request for a meeting, we will accept their request. There are many NGOs out there; we don't want to be perceived as giving particular attention to one of the NGOs. It may (lead to a) backlash (against) BPJS Kesehatan…. (*BPJS Kesehatan, Informant #3, Jakarta*)

This subsequently hinders a strategic and institutionalised approach, such that navigators resort to personal connections with JKN officers in order to facilitate access to health facilities. As such, the effectiveness of informal navigation to improve JKN responsiveness and to solve patients' problems often depends on the quality of these personal connections, as illustrated in the following quote:

> We often meet and visit friends at the hospital associations…by doing frequent meetings we develop good relationships. (*Navigator POSKO JKN KIS, Informant #49, Bekasi*)

Limits of individual case management

Interactions between JKN authorities and the navigation initiatives have not, however, necessarily led to systemic improvements in JKN responsiveness to patients. As our interviews with BPJS Kesehatan and Ministry of Health respondents revealed, inputs from navigators are received for individual cases only leading the JKN authority to respond to these as discrete issues without a sense of the systemic challenges as noted here:

> Navigators always come to us with cases: rejections, demanding access to certain individuals, status for poor non-salaried workers not getting access…but they never give us the aggregate data to convince me that the problem is everywhere…. (*BPJS Kesehatan, Informant #3, Jakarta*)

Even though the interaction between informal patient navigators and JKN authorities may not lead to systemic change, the navigators do not see this as a failure. Instead, the navigators claim that by presenting the list of issues in JKN implementation, they can trigger a nation-wide discussion on the reality of JKN.

DISCUSSION

The importance of patient navigation

In this study, we analysed how three informal patient navigation initiatives emerged (the context), are organised (content), operate (the process) and interact with formal navigation initiatives. We reflect on how these informal navigation initiatives contribute to empowerment of members and to increased responsiveness of JKN. In Indonesia these informal patient navigation initiatives were borne from labour union activism and as a response to the inadequate performance of formal navigation mechanisms to help citizens access their entitlements and to serve as patient advocates. These formal

initiatives were introduced to ensure JKN members were aware of their benefits and knew to access them. Yet despite good intentions at the launch of JKN in 2014, insufficient guidance, poor design, poor performance and structural barriers act as hindrances to availing the formal navigation initiatives.

Investigation of the content highlighted that when navigators are organised by solidarity-driven labour unions, patient navigation is likely underpinned by a passion for UHC objectives and a desire for social justice. Informal but effective means of communication as described under process have provided patients with an accessible, locally embedded and empathetic trusted person to turn to for various different types of assistance. Our study therefore offers insight into the variety of patient navigators that is important to reaching UHC objectives.

What was surprising and emerged in the study was the diversity in the interactions between key actors. While we had intended to explore interactions between informal and formal government patient navigation initiatives, we uncovered a unique set of relations between patients and JKN authorities, between the informal initiatives and JKN authorities and between informal initiatives and the media. These relations and their requisite interactions provide a much richer picture of opportunities for engagement, influence and change. Leveraging the various actors and their relative power on the JKN authorities as well as the public provide potentially untapped sources of power and pressure.

Finally, patient navigation initiatives are not unique to Indonesia. In countries where access to healthcare is limited, it is imperative to recognise the role of informal patient navigators in enhancing patient access. Our research adds to a previous scoping study on patient navigation services in China, Bangladesh, Iran, Pakistan, Guatemala, Brazil, India, Kenya, Mexico and Malaysia where navigators help family members, provide social support to patients, maintain communication between families, patients and health providers, facilitate the completion of paperwork, arrange transportation for patients and other services necessary to access covered health services.[24] Expanding the literature on informal patient navigators, our paper suggests that solidarity and UHC-driven patient navigation provides a viable alternative to the clientelistic nature of individual brokerage for 'mediated access to healthcare' as described by Berenschot et al.[17 18]

Limited effects on patient empowerment and JKN responsiveness

The context-content-process analysis from the Molyneux et al[19] framework proved useful in revealing the strengths as well as the weaknesses of informal patient navigation initiatives. It also shed light on the limited effects on patient empowerment and JKN responsiveness and ultimately on outcome indicators and UHC progress. This has implications for acknowledging the role of informal patient navigation and for improving interaction mechanisms within JKN.

The efforts of the patient navigators have neither fully translated into patients independently using health services or making use of the formal navigation mechanisms, nor have they significantly improved patients' confidence to communicate or interact with health providers. This study reveals that it is not for lack of effort but rather highlights the immense needs of the population that cannot possibly be filled by informal initiatives working at the individual level.

While we cannot report on an improvement in the number of grievances resolved for lack of data, we note that the informal navigation initiatives were unable to demonstrate a clear impact on enhancing JKN authorities' responsiveness. We surmise that this is likely due to informal navigation initiatives not capturing data systematically, working independently from each other and focusing solely on local cases. The interaction analysis revealed that they do not address the JKN authorities as a coalition which may be compounding the problem.

Policy and practice implications

Patient navigation initiatives are central to enabling access to benefits for those enrolled in health insurance programmes. The need to improve these and leverage their potential has implications for both JKN authorities as well as information patient navigators.

JKN authorities need to strengthen and improve the service quality of the formal patient navigation initiatives. Furthermore, they need to consider the variation of needs and capacity of members across areas in the design of these initiatives. These could include but are not limited to (1) ensuring adequate staffing of BPJS Satu officers in all hospitals, (2) providing regular refresher training to Care Center operators, (3) improving the JKN mobile interface and (4) providing cost-free access to those using Mobile JKN and Care Center. Routine data collection for monitoring JKN use would be critical to inform changes in regulations and policies. JKN authorities should create an institutionalised mechanism to absorb input from informal patient navigation initiatives as well as exploit synergies on a regular basis.

Informal patient navigators clearly fill a gap in Indonesia. Our results suggest however that some changes would be required to enhance their effectiveness. These include (1) investing in documenting their advocacy work and compiling the cases that they have handled; (2) using data to identify systemic problems underlying individual cases; (3) improving synergies with formal initiatives implemented by the JKN authorities (including by sharing the documented data); and (4) mobilising citizens nationwide to demand improvements to JKN design and implementation. Furthermore, informal patient navigation initiatives could leverage their relationship with the media to provide

regular updates and spur discussions on JKN regulation and implementation. Above all, in the quest for UHC, broader community involvement is needed to ensure access as promised by law.

Policymakers responsible for NHI in other countries could draw from this study as they consider strengthening formal patient navigation initiatives and also examine how informal patient navigation initiatives if any, can complement formal navigation efforts.

Study strengths and limitations

Our study fills an important gap in understanding NHI implementation in Indonesia. We perused multiple data sources, ensured triangulation, included member checking to enhance data trustworthiness and adhered to Consolidated criteria for Reporting Qualitative research reporting guidelines (see checklist in online supplemental file). It is the first study that systematically investigates the role of patient navigation, particularly the often-overlooked informal patient navigation initiatives in a NHI scheme seeking to progress towards UHC, which is high on the priority of many countries today. Our study sheds lights on the pros and cons of informal patient navigation initiatives and how they contribute to providing assistance where formal patient navigation initiatives have seemingly failed.

Unfortunately, the COVID-19 pandemic limited the number of interviews with informants, and we were unable to undertake full-day observations at hospitals as intended. Furthermore, our goal to understand the functioning of these informal navigation initiatives have led us to focus on geographical areas where we know that such initiatives exist. However, there may be other more localised initiatives in other regions of Indonesia that could function differently and have varied impacts on citizen access to insurance. Future studies could explore how different groups across different provinces in Indonesia initiate patient navigation and the extent to which the initiatives support the achievement of UHC.

CONCLUSION

This study demonstrates how informal patient navigation initiatives fill the gap created by the absence of functioning formal navigation initiatives in Indonesia. In the case of Indonesia, informal navigators have proved essential in assisting patients to access health services, particularly during medical emergencies. Unfortunately, due to the individualised nature of the response and the focus on the vulnerable, this has not translated into patient empowerment. Lack of data as well as uncoordinated efforts have also hampered their ability to increase JKN responsiveness. More is required from JKN authorities to enhance interaction with informal patient navigation initiatives in order to contribute to increasing use of JKN benefits,

to improved design informed by civil society and citizens' input, and to ensure appropriate care based on patients' needs. Similarly, synergies between informal navigation mechanisms and more rigorous documentation of their efforts are needed to provide JKN authorities with the necessary evidence to inform their decision-making.

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REFERENCES

1 World Health Organization and World Bank. Tracking universal health coverage: 2021 global monitoring report, World Health Organization, World Bank, Geneva [online], 2021. Available: https://www.who.int/publications/i/item/9789240040618

2 Asih EP, Thabrany H, Ramadani RV, *et al*. *Statistik JKN 2014-2018*. Jakarta: Dewan Jaminan Sosial Nasional & BPJS Kesehatan, 2020.

3 WHO. World Health Organization global health expenditure database per 2018 2018.

4 Bardan AB, Dewi HK. BPJS Kesehatan Targetkan Menambah 9.3 Juta Peserta Baru, Maksimalkan Kuota PBI 2022.

5 Nugroho AP, Handayani S, Effendi DE. Health citizenship and healthcare access in Indonesia, 1945-2020. *JSP* 2021;24:284–301.

6 Handayani L, Suharmiati S, Pratiwi NL. Unit cost rumah sakit DAN tarif INA-CBGS: Sudahkah pembiayaan pelayanan kesehatan rumah sakit dibayar dengan layak? *Bul Penelit Sist Kesehat* 2019;21:219–27.

7 Lilissurian S, Irwan R. Perbedaan biaya riil rumah sakit DAN tarif INA-CBGs untuk kasus katastropik dengan penyakit jantung koroner pada pasien rawat inap peserta Jaminan Kesehatan Nasional di RSUZA. *J Kesehat Masy* 2017;3:198–205.

8 Abdulah SS, Lorensia A. Analisis perbedaan biaya riil DAN tarif INA-CBG pasien hipertiroid di Rumah Sakit Universitas Hasanuddin. *Media Kesehat Masy Indones* 2020;16:421–6.

9 Mardhatillah M, Gunawan Tamtomo D, Murti B. An analysis of the difference between INA-CBG reimbursementand medical cost for patients with chronic renal disease: an evidence from Kasih Ibu Hospital, Surakarta in Revitalizing Family Planning Program and Women's Empowerment for the Improvement of Population Well-being and Economic Development 2018:221.

10 Thabrany H, Nugraha RR, Setiawan E. Narrowing the gap of inequity in the Indonesia's National Social Health Insurance Scheme, 2014-2018. *Res Sq*.

11 Freeman HP, Rodriguez RL. History and principles of patient navigation. *Cancer* 2011;117:3537–40.

12 Natale-Pereira A, Enard KR, Nevarez L, *et al*. The role of patient navigators in eliminating health disparities. *Cancer* 2011;117:3541–50.

13 Meade CD, Wells KJ, Arevalo M, *et al*. Lay navigator model for impacting cancer health disparities. *J Cancer Educ* 2014;29:449–57.

14 Manderson B, McMurray J, Piraino E, *et al*. Navigation roles support chronically ill older adults through healthcare transitions: a systematic review of the literature. *Health Soc Care Community* 2012;20:113–27.

15 Carter N, Valaitis RK, Lam A, *et al*. Navigation delivery models and roles of navigators in primary care: a scoping literature review. *BMC Health Serv Res* 2018;18:96.

16 Wells KJ, Valverde P, Ustjanauskas AE, *et al*. What are patient navigators doing, for whom, and where? a national survey evaluating the types of services provided by patient navigators. *Patient Educ Couns* 2018;101:285–94.

17 Berenschot W, Hanani R, Sambodho P. Brokers and citizenship: access to health care in Indonesia. *Citizensh Stud* 2018;22:129–44.

18 Berenschot W, van Klinken G. Informality and citizenship: the everyday state in Indonesia. *Citizensh Stud* 2018;22:95–111.

19 Molyneux S, Atela M, Angwenyi V, *et al*. Community accountability at peripheral health facilities: a review of the empirical literature and development of a conceptual framework. *Health Policy Plan* 2012;27:541–54.

20 Agustina R, Dartanto T, Sitompul R, *et al*. Universal health coverage in Indonesia: concept, progress, and challenges. *Lancet* 2019;393:75–102.

21 Cole R, Ford M. *The KAJS campaign for social security reform in Indonesia: lessons for coalitions for social change*. Jakarta: Friedrich Ebert-Stiftung, 2014.

22 Wisnu D. *Politik sistem jaminan sosial*. Jakarta: Gramedia Pustaka Utama, 2012.

23 Sedane Reporter. JamkesWatch: Isu kesehatan sebagai media berbaur dengan masyarakat luas 2018.

24 Dalton M, Holzman E, Erwin E, *et al*. Patient navigation services for cancer care in low-and middle-income countries: a scoping review. *PLoS One* 2019;14:e0223537.