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Exploring stakeholders' experiences and perceptions of barriers to effective surveillance of communicable diseases in a rural district of Pakistan – a qualitative study

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Naeem, Imran; Aga Khan University Medical College Pakistan, Community Health Sciences Department; Aga Khan University Siddiqi, Sameen; Aga Khan University Medical College Pakistan, Community Health Sciences Department Siddiqui, Amna Rehana; Aga Khan University, Community Health Sciences Hasan, Rumina; The Aga Khan University Hospital Main Campus Karachi; London School of Hygiene and Tropical Medicine Faculty of Public Health and Policy
International health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Organisation of health services < HEALTH SERVICES ADMINISTRATION & MANAGEMENT, Quality in health care < HEALTH SERVICES ADMINISTRATION & MANAGEMENT





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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

1 2

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Торіс	Item No.	Guide Questions/Description	Reported or Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with	5		
participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal	
the interviewer	,	goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?	
	0	e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.	
and Theory	5	grounded theory, discourse analysis, ethnography, phenomenology,	
and meory		content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience,	
Samping	10	consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,	
		email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-	15	Was anyone else present besides the participants and researchers?	
participants	15		
Description of sample	16	What are the important characteristics of the sample? e.g. demographic	
		data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot	
		tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	20	What was the duration of the inter views or focus group?	
Data saturation	21	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Торіс	Item No.	Guide Questions/Description	Reported on Page No.			
		correction?				
Domain 3: analysis and			•			
findings						
Data analysis						
Number of data coders	24	How many data coders coded the data?				
Description of the coding	25	Did authors provide a description of the coding tree?				
tree						
Derivation of themes	26	Were themes identified in advance or derived from the data?				
Software	27	What software, if applicable, was used to manage the data?				
Participant checking	28	Did participants provide feedback on the findings?				
Reporting			•			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?				
		Was each quotation identified? e.g. participant number				
Data and findings consistent 30		Was there consistency between the data presented and the findings?				
Clarity of major themes	31	Were major themes clearly presented in the findings?				
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?				
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Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

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6	2	Exploring stakeholders' experiences and perceptions of barriers to effective
7 8	3	surveillance of communicable diseases in a rural district of Pakistan – a
9	4	qualitative study
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13	6	Imran Naeem ^{1*} , Sameen Siddiqi ² , Amna Rehana Siddiqui ³ , Rumina Hasan ⁴
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15 16	7	
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18	8	¹ Assistant Professor, Community Health Sciences, Aga Khan University Karachi Pakistan
19 20	9	² Professor & Chair, Community Health Sciences, Aga Khan University Karachi Pakistan
20 21		
22	10	³ Consultant, Community Health Sciences, Aga Khan University Karachi Pakistan
23	11	⁴ Professor, Pathology & Laboratory Medicine, Aga Khan University Karachi Pakistan
24 25		
26	12	
27	13	*Corresponding author
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29 30	14	Email: Imran.naeem2009@gmail.com
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1 2		
2 3 4	19	ABSTRACT
5 6	20	Objective: To explore the experiences and perceptions of health system stakeholders of a
7 8	21	rural district of Sindh, Pakistan regarding the barriers to effective surveillance of
9 10 11 12 13 14	22	communicable diseases.
11	23	Design: This exploratory qualitative study comprised of in-depth interviews. An inductive
13	24	thematic analysis was applied to identify key themes from the data.
15	25	Settings: The study was conducted in public sector healthcare facilities and the district
16 17	26	health office of the rural district of Thatta, in Sindh province, Pakistan.
18 19	27	Participants: Fifteen healthcare managers and healthcare providers working in the eight
20 21	28	public sector primary and secondary healthcare facilities were interviewed using an open-
22	29	ended in-depth interview guide.
23 24 25	30	Results: Key themes that emerged from the data were: poor governance and absence of
26	31	surveillance policy framework; fragmentation in the health system leading to lack of uniform
27 28	32	reporting; inadequate (human) resources that weakened the infrastructure for disease
29 30	33	surveillance; hospital-based reporting of cases that led to a predominantly passive
30 31 32	34	surveillance system; paper-based surveillance system as the key determinant of delayed
33 34	35	reporting; non-utilization of surveillance data for decision making; absence of local
35	36	laboratory capacity to complement the detection of disease outbreaks and lack of private
36 37	37	sector integration in disease surveillance.
38 39	38	Conclusions: Poor governance and lack of policy framework were perceived to be
40 41	39	responsible for weak surveillance infrastructure. inadequate resource investment including
42 43	40	human resource, paper-based reporting and the absence of local laboratory capacity was
44	41	considered to result in delayed, poor, and inadequate reporting. The lack of private sector
45 46	42	engagement was identified as a major gap.
47 48	43	
49 50		Konnerde surveillance, communicable diseases, bealth corniaes research, qualitative
51 52	44	Keywords: surveillance, communicable diseases, health services research, qualitative
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Strengths and limitations of this study

- The study comprehensively explored the barriers and perceptions to effective disease surveillance by interviewing a diverse group of key stakeholders that were directly engaged in service delivery at the district level
- Adopting a qualitative approach provided a deeper insight into the challenges faced by district health system stakeholders in disease surveillance
- do. . availab. . istricts of Pak. . n a similar context. The study was conducted in a predominantly rural district of Pakistan that is already challenged in terms of resource availability. Despite that state of disease surveillance is more or less similar in most districts of Pakistan when generalizing the study findings, these may be interpreted in a similar context.

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BACKGROUND

Infectious diseases continue to pose threat to the health of the public globally. In developing countries, infectious diseases form a significant portion of the disease burden including HIV/AIDS, tuberculosis (TB), malaria, respiratory infections, hepatitis B & C in adults and pneumonia and diarrhoea in children under five years of age ¹². In Pakistan, communicable diseases remain a major cause of public health concern with a significant contribution to morbidity and mortality. Conditions like overcrowding, low socio-economic status, poor hygiene and unsafe drinking water and poor awareness of health lead to an environment conducive to disease outbreaks. The Health System of the country is toppled by issues of poor governance and lack of resources resulting in a disease surveillance system that is inept at detecting disease outbreaks ³. Before the devolution of the health system, Pakistan had two main sources to collect data for health indicators namely: 1) health management information system: this was designed to collect data on selected health indicators from health facilities with established reporting lines from provincial to federal health ministry; 2) data from vertical programs such as national TB control program, malaria control program, HIV/AIDS control program amongst others ⁴. Following health system devolution in 2010, administrative powers were devolved to provinces with the district becoming the autonomous unit for defining its health priorities and health planning ⁵. In the new, albeit ill-prepared administrative setup district health information system (DHIS) was established to collect disease-related data from the health facility level. In all provinces of the country including the Sindh province, DHIS is the major or only source of information on health indicators of the population presenting to public sector health facilities. However, the DHIS has remained underutilized for communicable disease surveillance. In the last five years, rural districts of Sindh have seen outbreaks of diseases including measles ⁶ and HIV/AIDS ⁷ in children pointing out a surveillance system weak at detecting outbreaks. As per the international health regulations, member states of the World Health Organization have the obligation to develop and strengthen disease surveillance with the help of existing health system resources ⁸. However, the emergence of recent outbreaks has indicated weaker surveillance of communicable diseases more so in rural areas. Moreover, only those diseases with global priority (such as COVID-19 and Polio) manage to get attention, whereas surveillance for diseases of national priority is often unable to compete with other health

priorities for policy space and resources. There often is reliance on disease numbers to
highlight weak surveillance. But perceptions and experiences of those at the forefront of
service delivery are less well studied in Pakistan. Hence, we conducted this study to explore
the experiences and perceptions of health system stakeholders of a rural district of Sindh,

91 Pakistan regarding the barriers to effective surveillance of communicable diseases.

METHODS

93 Study design and setting

This study used a descriptive exploratory design to explore the perceptions and experiences of district health system stakeholders regarding the barriers to an effective surveillance system for communicable diseases in the rural district of Thatta located in the province of Sindh, Pakistan. Thatta is situated approximately 100 kilometres from the provincial capital of Karachi. It is a predominantly rural district with an approximate population of 1 million ⁹ ¹⁰. Health indicators including maternal mortality ratio and neonatal mortality rate are amongst the worst in the country ^{11 12}. The situation of the healthcare system of Thatta is comparable to any other rural district of Pakistan with inadequate infrastructure and resources. There exist primary and secondary healthcare facilities in the district and there is also a private healthcare system in the district comprising general practitioner clinics and small hospitals. The study was conducted from February 15 to April 30, 2022, in eight public sector primary and secondary healthcare facilities in the district.

106 Study participant

We used purposive sampling to select study participants. Eligible participants were
healthcare managers and healthcare providers working in the eight public sector primary
and secondary healthcare facilities. Healthcare managers were those working at the district
level and were responsible for the management of health services. Healthcare providers
were the doctors responsible for the provision of clinical care at selected healthcare
facilities. Participants included both males (n = 12) and females (n = 3). The age range of
study participants was 29 – 57 years.

We used the 'saturation principal' to determine the sample size for the study. Upon
researchers' observation, with further interviews yielding no added information and

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producing no new or significant findings, data collection was stopped. This resulted in 15 in-116 depth interviews with healthcare managers and healthcare providers. 117

Data collection 118

The data were collected using an open-ended interview guide. The interview guide was used 119 120 to conduct in-depth interviews for exploring participants' perceptions and experiences with the surveillance system for communicable diseases in the Thatta district. The interview 121 122 guide was developed by researchers after a thorough literature search on the subject and a 123 review of literature in line with the objective of the research. The interview guide contained open-ended questions regarding perceptions and experiences about the current state of the 124 surveillance system of communicable diseases, challenges faced in terms of resources, 125 infrastructure and financing, and barriers faced in terms of reporting, timeliness, and data 126 127 quality. The interview guide was piloted before data collection. The interviews were 128 conducted by the first author (IN) who has research experience in health systems and communicable diseases and qualitative research. The first author moderated the interviews 129 along with note-takers. The interviews were conducted in the local language (Sindhi) and 130 131 were audiotaped. The first author and the note takers held a debriefing session after each interview to reflect on the participants' responses. The interviews took place in health 132 facilities at a time suitable for study participants with each interview lasting about 20 – 35 133 134 minutes. Researchers had formal links established with the study respondents due to their 135 four years long work experience with stakeholders of the Thatta district. The study 136 participants were explained the study objective, and any queries raised before data collection were satisfied. 137

Ethical considerations 138

Informed written and verbal consent was obtained from all study participants. Ethical 139 approval for this study was obtained from the Ethics Review Committee of the Aga Khan 140 University Karachi, Pakistan (ERC # 2020-5777-15184). Privacy, confidentiality, and 141 anonymity of the respondents were ensured during data collection and reporting of the 142 study findings. 143

1 2		
3 4	145	Researchers' characteristics
5 6	146	In qualitative research, research findings have the potential to be influenced by the study
7 8	147	settings and researchers' interest and understanding of the topic. In this study, researchers
9 10	148	were not the staff of the health facilities where the study was conducted. However, due to
11 12	149	the researchers' four years' work experience in the district, they were considered by the
13 14	150	study respondents to be someone familiar with the district health system and its challenges
15	151	and with an interest in exploring their perceptions and experiences regarding the challenges
16 17 18	152	that the district might be facing in terms of disease surveillance.
19 20	153	Patient and public involvement statement
21 22	154	Patients or the public were not involved in the design, or conduct, or reporting, or
23	155	dissemination plans of our research
24 25	156	DATA ANALYSIS
26 27	157	We used the inductive method to perform data analysis. The analysis approach used a
28 29	158	combination of interviews with study participants facilitated by field observations. The first
30 31	159	author transcribed all audio tapes from Sindhi to English and wrote interview notes. Manual
32 33	160	content analysis was performed where interview notes were read and re-read to identify
34 35	161	similarities and differences of perspectives among study participants. Similar perspectives
36 37	162	were grouped and classified into main themes. All the authors and field team members read
38	163	the themes, and discrepancies were discussed during the interpretation and analysis of
39 40	164	data. The themes emerging from the analysis were shared and discussed with study
41 42	165	participants for their comments.
43 44	166	RESULTS
45 46 47	167	Data analysis identified a number of core themes from the experiences and perceptions of
48	168	healthcare managers and healthcare providers regarding the surveillance system of
49 50	169	communicable diseases. Where appropriate, verbatim quotations from the interview
51 52	170	transcripts have been used to ensure rigour in the reporting of data. To avoid identifying
53 54	171	specific individuals, the participants have been allocated aliases.
55 56	172	The absence of a surveillance policy framework and poor governance leads to an ill-
57 58 59	173	defined disease surveillance system
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3 4	174	All study participants unanimously pointed out the lack of a comprehensive policy
5 6	175	framework for disease surveillance. As a result, there is a lack of clarity in reporting disease-
7	176	related data, coordination between different stakeholders, and meaningful analysis of data
8 9 10	177	and its use for taking action.
11 12	178	"National health policy emphasizes the importance of disease surveillance and having such a
13 14	179	system in place; however, it is up to provinces to develop detailed guidelines for disease
15 16	180	surveillance and ensure its implementation which is not happening! [Participant 14]."
17 18	181	Provincial disease surveillance and response unit
19 20 21	182	A digital system named Provincial Disease Surveillance and Response Unit (PDSRU) was
22	183	developed a few years ago with the support of donor money. The PDSRU had all the
23 24	184	communicable diseases of importance listed and the system was expected to be linked up
25 26	185	with secondary hospitals in the province for regular data collection. However, interview
27 28	186	respondents commented that the PDSRU unit has remained dysfunctional and has not been
29 30	187	utilized for the purpose it was built for.
31 32	188	"It is very unfortunate that we got the donor money to establish a surveillance system in the
33 34 35	189	province, but we didn't plan for resources to make the system functional [participant 5]."
36 37	190	District health information system
38 39	191	The DHIS has existed longer than the PDSRU, has the service delivery data collated from
40 41	192	primary and secondary health facilities and the frequency of reporting is monthly. The data
42 43	193	is collected on paper at the health facility level and a hard copy of the monthly DHIS
44	194	reporting form is handed over physically by each facility to the district health office. There, a
45 46	195	computer operator enters the data into the digital portal of DHIS which then can be viewed
47 48 49	196	on a dashboard.
50	197	In the current state, DHIS is the only functional health information system that has up-to-
51 52 53 54	198	date disease information. However, this information remains underutilized for disease
	199	surveillance as there is hardly any review and feedback on the reported data from the
55 56	200	district health office or provincial health department. Moreover, since the data is collated
57 58 59 60	201	and shared at the end of each month, its utility for detecting disease outbreaks is limited.

"DHIS data can be a very good source of passive surveillance, but we need to increase the reporting frequency from monthly to weekly and have regular reviews of the reported data [Participant 5]." Communicable Disease Control unit The Communicable Disease Control (CDC) unit was built at the provincial level with the intent to integrate all the vertical (disease-specific) programs under one roof for planning, resource allocation and intervention. Under the CDC unit, blood-borne diseases like HIV/AIDS, hepatitis C and hepatitis B could be looked after single-handedly when addressing the mode of spread, designing interventions and surveillance. Unfortunately, the unit lacks any infrastructure, dedicated human resources and disease integration plan at the district level. "Having CDC presents an immediate opportunity for syndromic surveillance; we should not waste this opportunity [Participant 10]." Fragmentation in the healthcare system is a hindrance to a uniform reporting system Under the public-private partnership (PPP), the public sector healthcare system in Thatta has been contracted out to various private providers. Under PPP, these providers are responsible for providing health services on a day-to-day basis while the health department provides a budget. However, due to extensive contracting out each level of health facility (i.e., primary, and secondary) is managed by a different private partner. Distinct reporting lines and a lack of data sharing mechanisms between private partners have given rise to fragmentation within the district health system. "Primary level facilities are supposed to be linked with secondary level facilities for referrals and reporting of disease-related data, however, there are so many partners with each having its reporting line. This has negatively affected the reporting of disease surveillance [participant 10]." At the district level, surveillance for vaccine-preventable diseases (VPDs) is conducted by the district health office with the district surveillance coordinator as the focal point. Whereas notifiable diseases are reported by the focal persons of the disease-specific programs with a flow of information that is separate from that of VPDs. This vertical nature of surveillance of

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different diseases is inefficient in terms of resource utilization as it creates parallel systems
where surveillance activities are carried out in siloes. These inefficiencies in turn create a
weaker surveillance system and put the population at higher risk for communicable disease
outbreaks.

235 "Every disease-specific program such as that of tuberculosis, malaria etc reports its data in
236 isolation, how can we have an integrated disease surveillance system in this situation?
237 [Participant 7]."

238 Inadequate resources translate to poor disease surveillance

In the district health office, there is a district surveillance coordinator who is mandated to
 look after the surveillance of VPDs in the district. He is solely responsible for coordinating
 with all eight public sector health facilities of the district, ensuring the timely collection of
 surveillance data and its reporting. He is also responsible for entering the disease-related
 information into the district health information system. This not only leads to increased
 workload but often time leads to delayed data entry and communication of this information
 to district health stakeholders.

Not only that he lacks a team of dedicated individuals for surveillance, but he also has no provision of transportation for reaching out to health facilities and communities for active surveillance. Most of the time, he has to rely on making telephonic contact with each in charge of health facilities to get disease-related information.

Currently, reporting for VPDs is mandatory and health facilities are required to send weekly
 reports (even for no cases called 'zero reports') of VPDs to the district surveillance
 coordinator. However, due to a lack of resources such as transportation and dedicated
 surveillance staff, the reports from various health facilities in the district often get delayed.

254 "Expecting one person to lead disease surveillance in the district, in the absence of
 255 transportation and adequate human resource is too much to ask [Participant 2]."

For notifiable diseases, the district focal persons of disease-specific programs have the
 responsibility to report the number of cases of the disease. The primary role of the focal
 person is program implementation which involves numerous tasks from planning and
 implementing to monitoring and reporting program activities. In absence of adequate

human resource, focal persons primarily rely on data reported as part of program implementation. This has limitations namely 1) this is a form of passive surveillance rather than active; 2) reporting of program data takes place at specific intervals whereas surveillance requires continuous monitoring of disease cases and prompt action. These limitations lead to a disease surveillance system that struggles with timely detection, and reporting of disease outbreaks. The current surveillance system is hospital-based Study respondents pointed out that since the data collection is passive as it is collected largely from those patients that present to health facilities, hence it is a form of passive surveillance rather than active surveillance. "We could be missing out on outbreaking at the community level since there is no one going and actively screening the community members [Participant 1]" Respondent attributed the lack of community-based active surveillance to a lack of resources and mentioned that there is a need to increase resource allocation for strengthening active surveillance. Paper-based reporting is a key determinant of delayed disease reporting The system for reporting health-related data from health facility to district health office in Pakistan is paper-based for both vaccine-preventable diseases and notifiable diseases. In this system, the health facility in-charge fills out a zero-reporting form or a case report for a notifiable disease. A physical copy of this report is then sent to the district surveillance officer. This often gets delayed as someone must visit either the health facility or the office of the district surveillance coordinator to deliver the physical copy of the report. To prevent delay, telephonic contact often plays a key role, however, it is not a feasible way to disseminate the information to all the relevant stakeholders. "We should have a digital system with a dashboard which can show data in real-time. We will avoid delayed reporting forever [participant 2]." Surveillance data is underutilized for evidence-based decision making

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3 4 5 6 7 8	287	The majority of study respondents mentioned that data verification is essential to ensure its
	288	fidelity. To ensure data quality, monitoring and supervision of field staff and the facility
	289	healthcare staff sending data need strengthening.
9 10	290	In the existing system of disease surveillance, there is an emphasis on data collection only.
11 12	291	No monitoring and supervision are happening from the district or provincial levels. Other
13	292	than the circumstances where a suspected or confirmed case of disease under surveillance
14 15 16 17 18	293	is reported, there is no action taken to verify the authenticity and quality of routinely
	294	reported data.
19 20	295	"Despite that, the data is regularly collected through DHIS and other channels, it is rarely
21 22	296	reviewed or utilized for analysis or action [Participant 12]."
23 24 25	297	Lack of laboratory testing capacity takes a toll on disease surveillance
26 27 28	298	Among the eight public sector health facilities in the Thatta district, only two have clinical
	299	laboratories. However, none of these laboratories is equipped to conduct testing for any of
29 30	300	the VPDs or notifiable diseases in the district. Biological samples collected from suspected
 31 32 33 34 35 36 37 38 39 40 41 42 43 	301	patients are sent to a regional laboratory that is based in the capital city of the country
	302	(laboratory at National Institute of Health, Islamabad) situated at least 1000 kilometres from
	303	Thatta district.
	304	The absence of a fully equipped laboratory nearby calls for measures to ensure proper
	305	storage and transportation of biological samples. This not only is resource-intensive but
	306	adds to the delays in the system staggered by issues of delayed reporting.
44 45	307	"Provincial health department should, at the least, take measures to build a laboratory in the
46 47	308	province so that disease surveillance can be made a little more efficient [Participant 6]."
48 49 50 51 52 53 54 55 56 57 58	309	The lack of integration of the private sector in disease surveillance is a major gap
	310	The private health sector is a major stakeholder in service delivery and caters to
	311	approximately 70% healthcare needs of the population. Unfortunately, however, the service
	312	delivery data of the private health sector is not integrated into the DHIS of the public health
	313	sector. In fact, the government is still lagging in taking measures to regulate the private
	314	health sector in Sindh province.
59 60		

Integration of data from the private sector in the health information system is essential to ensure effective disease surveillance as currently, a significant chunk of the population's disease burden remains to be captured. "Our disease surveillance will be at a loss from capturing the true disease burden unless it integrates data from the private health sector [Participant 6]." DISCUSSION Our study explored multifaceted barriers to effective surveillance of communicable diseases in a rural district of Pakistan. Findings showed that while infrastructure for surveillance at the provincial level is underutilized, structural challenges such as resource deficiencies (including human resource), poor coordination among stakeholders for sharing data, absence of private sector involvement, paper-based reporting, and lack of utilization of data for decision making are some of the key challenges at the district level. Though it has been over a decade since the devolution of the health system in Pakistan, the pace of provinces leading health planning has remained rather sluggish. Given the increasing disease outbreaks in Sindh and other provinces in recent years i.e., measles, HIV/AIDS and the global COVID pandemic, the need for comprehensive guidelines and laws for disease surveillance has grown stronger. Study participants were concerned about the delay in taking initiatives for the development of surveillance guidelines at the provincial level. This experience is similar to other lower and lower-middle-income countries. Studies from Nigeria and Zambia show that the laws related to public health surveillance existed but were considered to be outdated and/or poorly implemented ¹³. Studies from Iran and Palestine concluded that having laws and policies for disease surveillance enable governments to allocate funds for establishing surveillance programs and that health authorities should play a lead role in ensuring their implementation ^{14 15}. Having a dysfunctional PDSRU for reporting surveillance data is a classic example of relying on donor money instead of concentrating on building local capacity toward a functional information system. Many respondents termed this unfortunate and emphasized investing resources in reviving the PDSRU which was already there. In a study from China inadequacy of resources at the local level was termed as the key factor affecting the effectiveness of disease surveillance. The study reported that the top tier of government invests more in

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3 4	345	building digital information systems, but lower levels don't receive enough planned
5 6	346	resources to ensure its implementation ¹⁶ . A functional digital information system has been
7	347	found to speed up the reporting, improve data flow and ensure the availability of up-to-date
8 9	348	data for the decision-makers. This eventually leads to early detection of outbreaks and
10 11	349	timely action ¹⁴ . Having the district surveillance coordinator as the sole person responsible
12 13	350	for surveillance activities in the district without any additional resources was considered the
14 15	351	major weakness in the surveillance system by study respondents. Literature shows that
16 17	352	during an epidemic, there is an increase in the workload requiring more human resource
18	353	and support for efficient data reporting ¹⁷ . The resource deficiencies including field-based
19 20	354	staff have been shown to undermine effective disease surveillance ^{15 18} . Moreover, putting
21 22	355	an extra burden of surveillance activities on healthcare providers alongside the service
23 24	356	delivery affects their motivation, performance, and quality of reporting ^{14 16 19} .
25 26	357	Despite several advantages of contracting out of health services that the literature notes,
27	358	the structural challenges largely remain unaddressed ²⁰ . One such structural challenge is
28 29	359	poor coordination between stakeholders. Many respondents pointed out that having
30 31	360	multiple stakeholders in the same district had been detrimental to disease surveillance due
32 33	361	to a lack of coordination and ambiguous reporting lines. The flow of data is independent of
34 35	362	the level of health facility defeating the notion of integrated disease surveillance. Similarly,
36 37	363	disease-specific programs (malaria, dengue), that have a strong component of
38	364	environmental control measures, lack integration with the public health engineering
39 40	365	department. A study from India attributed the inefficiency in reporting dengue surveillance
41 42	366	data to poor integration of health services ¹⁸ . Poor coordination between health and other
43 44	367	sectors ¹⁷ and between various levels of health facilities ¹⁴ has been reported to affect not
45 46	368	just the data reporting but also may lead to a lack of trust among stakeholders.
47 48	369	The current system for reporting diseases is a form of passive surveillance as it is hospital-
49	370	based, and data is gathered from patients presenting to health facilities. Literature shows
50 51	371	that the majority of people may not opt to show up unless they have serious symptoms 16 .
52 53	372	This, in the event of a communicable disease, not only has the potential for the spread of
54 55	373	infection but also may cause a delay in detecting an outbreak. Relying on passive
56 57	374	surveillance only is often dependent on factors including patients' awareness and health-
58 59	375	seeking behaviours and socioeconomic status and hence needs to be supplemented by
60	376	some form of active surveillance ¹⁹ .

Paper-based reporting in our study came out as an important barrier to timely reporting. The need for transitioning from slow, staff reliant and paper-based reporting to the digital mode of reporting is increasingly recognized in literature ^{14 17} and a study from India has demonstrated improved disease notification and enhanced data reporting due to transitioning to digital media²¹. Except when suspected or a confirmed case of a disease is detected, data sent from health facilities is rarely reviewed at higher levels. Respondents in our study pointed out that there is more emphasis on data collection than its analysis and use. It is evident from the Literature that providing regular feedback to facility staff on the data has been shown to act as a motivating factor and a performance boost ¹⁴ ¹⁸. Respondents in our study cited the lack of local laboratory capacity in the district as an important gap in detecting disease outbreaks. Studies in literature have demonstrated that in absence of a local laboratory, rapid diagnostics kits (RDTs) may facilitate confirming outbreak until laboratory test results become available ¹⁹ thus preventing delays that may incur in the transfer of biological samples. However, despite being cheap, resource investment is still required to ensure their uninterrupted availability ¹⁸. The extent to which a health system can detect disease outbreaks is dependent on its capacity to capture patients' data. In Pakistan, the private health sector caters to the majority of the population's healthcare needs. However, it is largely unregulated, particularly in Sindh province leading to a lack of integration of its patient data with the public sector. Studies show that the poor private sector engagement in disease surveillance is an important issue hampering the surveillance efforts in many countries including India ¹⁸ ²¹, Iran ²² and China ¹⁹. LIMITATION Our study was conducted in a predominantly rural district of Pakistan that is already challenged in terms of resource availability. Hence, when generalizing the study findings, these may be interpreted in a similar context. However, the state of disease surveillance is more or less similar in the country and hence experiences and perceptions given are relatable to several districts of the country. CONCLUSION

1 2		
3 4 5	407	We concluded that poor governance was perceived to lead to underutilization of existing
	408	resources for surveillance whereas lack of a policy framework on surveillance was
6 7	409	considered to lead to a poor investment of resources in surveillance infrastructure. The
8 9	410	absence of resources and inadequate human resource was identified by respondents as the
10 11	411	key determinant of delayed and inadequate reporting leading to delayed detection of
12 13	412	disease outbreaks. This was further aggravated by the absence of local laboratory capacity.
14 15	413	The existing surveillance system was perceived as largely paper-based, slow, and comprised
16	414	of hospital-based passive surveillance. The lack of private sector engagement in
17 18 19 20	415	communicable disease surveillance was perceived as a significant gap.
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	437	List of abbreviations
42	438	TB – Tuberculosis
43 44	439	List of abbreviations TB – Tuberculosis DHIS – District health information system DDSRU – Provincial Disease Surveillance and Persponse Unit
45 46	440	PDSRU – Provincial Disease Surveillance and Response Unit
47 48	441	CDC – Communicable Disease Control
49 50	442	PPP – Public-private partnership
51	443	VPDs – Vaccine preventable diseases
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Exploring stakeholders' experiences and perceptions regarding barriers to effective surveillance of communicable diseases in a rural district of Pakistan – a qualitative study

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4	1	TITLE:
5 6	2	Exploring stakeholders' experiences and perceptions regarding barriers to
7 8	3	effective surveillance of communicable diseases in a rural district of Pakistan
8 9	4	– a qualitative study
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13 14	6	Imran Naeem ^{1*} , Sameen Siddiqi ² , Amna Rehana Siddiqui ³ , Rumina Hasan ⁴
15	7	
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18	8	¹ Assistant Professor, Community Health Sciences, Aga Khan University Karachi Pakistan
19 20	9	² Professor & Chair, Community Health Sciences, Aga Khan University Karachi Pakistan
21 22	10	³ Consultant, Community Health Sciences, Aga Khan University Karachi Pakistan
23 24	11	⁴ Professor, Pathology & Laboratory Medicine, Aga Khan University Karachi Pakistan
25	12	
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28	13	*Corresponding author
29 30	14	Email: Imran.naeem@aku.edu
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3 4	19	ABSTRACT
5 6	20	Objective: To explore the experiences and perceptions of health system stakeholders of a
7 8	21	rural district of Sindh, Pakistan regarding the barriers to effective surveillance of
9 10	22	communicable diseases.
11 12	23	Design: This qualitative descriptive exploratory design comprised in-depth interviews. Both
13	24	inductive and deductive thematic analysis was applied to identify key themes from the data.
14 15	25	Settings: The study was conducted in public sector healthcare facilities and the district
16 17	26	health office of the rural district of Thatta, in Sindh province, Pakistan.
18 19	27	Participants: Fifteen healthcare managers and healthcare providers working in the eight
20 21	28	public sector primary and secondary healthcare facilities were interviewed using an open-
22 23	29	ended in-depth interview guide.
24	30	Results: Key themes that emerged from the data were: poor governance and absence of
25 26	31	surveillance policy framework; fragmentation in the health system leading to lack of uniform
27 28	32	reporting; inadequate (human) resources that weakened the infrastructure for disease
29 30	33	surveillance; hospital-based reporting of cases that led to a predominantly passive
31 32	34	surveillance system; paper-based surveillance system as the key determinant of delayed
33 34	35	reporting; non-utilization of surveillance data for decision making; absence of local
35	36	laboratory capacity to complement the detection of disease outbreaks and lack of private
36 37	37	sector integration in disease surveillance.
38 39	38	Conclusions: Poor governance and lack of policy framework were perceived to be
40 41	39	responsible for weak surveillance infrastructure. Resource deficiencies including inadequate
42 43	40	human resource, paper-based reporting and the absence of local laboratory capacity were
44	41	considered to result in delayed, poor quality, and incomplete reporting. The lack of private
45 46 47	42	sector engagement was identified as a major gap.
48 49	43	
50 51	44	Keywords: surveillance, communicable diseases, health services research, qualitative, rural,
52 53	45	Pakistan
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	St	rengths and limitations of this study
47	•	The study has explored experiences and perceptions regarding barriers to effective
48		surveillance of communicable diseases in-depth by involving representatives from
49		various levels of the healthcare system including from the public health sector and those
50		working under public-private partnership
51	•	The inclusion of both healthcare managers and healthcare providers in the study
52		provided deeper insights into barriers at both the stewardship level and the operational
53		level
54	•	The study is amongst few in Pakistan to adopt a qualitative research approach for
55		exploring barriers to infectious disease surveillance as perceived and experienced by
56		health system stakeholders
		exploring barriers to infectious disease surveillance as perceived and experienced by health system stakeholders

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BACKGROUND

Infectious diseases continue to pose threat to the health of the public globally. In developing countries, infectious diseases form a significant portion of the disease burden including HIV/AIDS, tuberculosis (TB), malaria, respiratory infections, hepatitis B & C in adults and pneumonia and diarrhoea in children under five years of age ¹². In Pakistan, communicable diseases remain a major cause of public health concern with a significant contribution to morbidity and mortality. Conditions like overcrowding, low socio-economic status, poor hygiene and unsafe drinking water and poor awareness of health lead to an environment conducive to disease outbreaks. The Health System of the country is overwhelmed by issues of poor governance and lack of resources resulting in a surveillance system that is ill-equipped at detecting outbreaks of infectious disease ³. Before the devolution of the health system, Pakistan had two main sources to collect data for health indicators namely: 1) health management information system: this was designed to collect data on selected health indicators from health facilities with established reporting lines from provincial to federal health ministry; 2) data from vertical programs such as national TB control program, malaria control program, HIV/AIDS control program amongst others that also reported to federal health ministry ⁴. Following health system devolution in 2010, administrative powers were devolved to provinces with the district becoming the autonomous unit for defining its health priorities and health planning⁵. In the new, albeit ill-prepared administrative setup district health information system (DHIS) was established to collect disease-related data from the health facility level ⁶. In all provinces of the country including the Sindh province, DHIS is the only source of information on health indicators of the population based on service delivery data from public sector health facilities. However, the DHIS has remained underutilized for communicable disease surveillance. In the last five years, rural districts of Sindh have witnessed outbreaks of diseases such as measles ⁷ and HIV/AIDS ⁸ while the surveillance system was unable to predict these outbreaks. As per the international health regulations, member states of the World Health Organization have the obligation to develop and strengthen disease surveillance with the help of existing health system resources ⁹. However, the emergence of recent outbreaks has indicated weaker surveillance of communicable diseases more so in rural areas of Pakistan. Moreover, only diseases with global priority (such as COVID-19 and Polio) have managed to get attention, whereas

surveillance for diseases of national priority has often struggled to compete for policy space and resources. The scientific literature on infectious disease surveillance in Pakistan is either quantitative in nature or mostly has discussed the implementation of models like the disease early warning system (DEWS) for surveillance ¹⁰⁻¹². However, there is a dearth of literature regarding the challenges that healthcare managers and providers face when implementing disease surveillance programs and perceptions and experiences of these healthcare professionals regarding barriers to effective surveillance of infectious diseases are less well studied in Pakistan. Such information will not only give an in-depth insight into the challenges faced in infectious disease surveillance but also inform the policy makers with recommendations for addressing those challenges. Hence, we conducted this study to explore the experiences and perceptions of health system stakeholders of a rural district of Sindh, Pakistan regarding the barriers to effective surveillance of communicable diseases.

101 METHODS

102 Study design and setting

This study used a qualitative descriptive exploratory design to explore the perceptions and experiences of district health system stakeholders regarding the barriers to an effective surveillance system for communicable diseases in the rural district of Thatta located in the province of Sindh, Pakistan. Thatta is situated approximately 100 kilometres from the provincial capital of Karachi. It is a predominantly rural district with an approximate population of 1 million ^{13 14}. Health indicators including maternal mortality ratio and neonatal mortality rate are amongst the worst in the country ¹⁵¹⁶. The situation of the healthcare system of Thatta is comparable to any other rural district of Pakistan with inadequate infrastructure and resources. There exist primary and secondary healthcare facilities in the district and there is also a private healthcare system in the district comprising general practitioner clinics and small hospitals. The study was conducted from February 15 to April 30, 2022, in eight public sector primary and secondary healthcare facilities in the district.

56 116 Study participants

We used purposive sampling to select study participants. Eligible participants were
 healthcare managers and healthcare providers working in the eight public sector primary

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and secondary healthcare facilities. Healthcare managers were those working at the district
level and were responsible for the management of health services. Healthcare providers
were the doctors responsible for the provision of clinical care at selected healthcare
facilities. Participants included both males (n = 12) and females (n = 3). The age range of
study participants was 29 – 57 years. The experience of study participants with the district
health system ranged from 5 – 30 years.

We used the 'saturation principle' to determine the sample size for the study. Upon
 researchers' observation, with further interviews yielding no new or significant findings,
 data collection was stopped. This resulted in 15 in-depth interviews with healthcare
 managers and healthcare providers.

129 Data collection

130 The data were collected using an open-ended interview guide. The guide comprised questions and probes regarding perceptions and experiences about the current state of 131 132 communicable disease surveillance and challenges in infrastructure and financing for surveillance, barriers in data reporting, timeliness of reporting, and quality of reported data. 133 The guide was developed following a thorough literature review and researchers' own 134 experience and expertise on the subject. The guide was piloted before data collection. 135 Based on the pretest results, researchers gained new insights and revised the interview 136 137 guide by adding further questions and probes. The interviews were conducted by the first 138 author (IN) having research experience in health systems, communicable diseases, and 139 qualitative research. The first author moderated the interviews along with note-takers. The interviews were conducted in the local language (Sindhi) and were audiotaped. A debriefing 140 session was held after each interview to reflect on the participants' responses. The 141 interviews took place in health facilities at a time suitable for study participants with each 142 interview lasting about 40 – 50 minutes. 143

144 Ethical considerations

Informed written and verbal consent was obtained from all study participants and queries
 raised were satisfied. Ethical approval for this study was obtained from the Ethics Review
 Committee of the Aga Khan University Karachi, Pakistan (ERC # 2020-5777-15184). Privacy,

148 confidentiality, and anonymity of the respondents were ensured during data collection and149 reporting of the study findings.

Researchers' reflexivity

In qualitative research, research findings are liable to be influenced by researchers' interest and understanding of the topic. In this study, researchers were not the staff of the health facilities where the study was conducted. However, due to the research team's four years' work experience in the district, they were not considered outsiders by the study respondents but rather someone familiar with the district health system and interested in exploring their views. Moreover, researchers used reflexive notes during data collection that fed into the interpretation of study findings to minimize researcher bias. Researchers had knowledge of the health system and infectious diseases research which influenced the development of the interview guide, however, while pre-testing the guide researchers gained new knowledge which informed the revision of the interview guide.

2728 161 Patient and public involvement statement

Patients or the public were not involved in the design, or conduct, or reporting, or

³¹₃₂ 163 dissemination plans of our research

³³₃₄ 164 **DATA ANALYSIS**

We used both inductive and deductive methods to perform data analysis. The analysis approach used a combination of interviews with study participants facilitated by field observations. Researchers' background knowledge of health systems and infectious disease research guided the process of data collection and analysis using the deductive method. However, during the analysis new themes emerged that were analysed using the inductive method. All audio tapes were transcribed from Sindhi to English and interview notes were written. Manual content analysis was performed where interview notes and notes from audio transcripts were read and re-read to identify patterns in data. Manual codes were assigned to identified patterns in data which were subsequently grouped and classified into main themes. All the authors and field team members read the themes, and discrepancies were discussed during the interpretation and analysis of data. The themes emerging from the analysis were shared and discussed with study participants for their comments.

9	RESULTS		
0	Data analysis identified a number of core themes from in-depth interviews. Whe		
appropriate, direct quotes from the interviews have been used to ensure rigour			
	reporting. To avoid identifying specific individuals, the participants have been allocated		
	aliases. Table 1 summarizes the themes and codes that emerged from the data.		
Table 1. Themes and codes emerging from data			
	Themes	Codes	
	The absence of a surveillance policy	• Lack of provincial policy on infectious	
	framework and poor governance leads to	disease surveillance	
	an ill-defined disease surveillance system	Lack of laws	
		Lack of surveillance standards	
		• Lack of resource planning leading to	
		dysfunctional digital information	
		systems	
		• Lack of planning to ensure integrated	
		surveillance of infectious diseases	
	Fragmentation in the healthcare system is a	Poor coordination between health	
	hindrance to a uniform reporting system	system stakeholders	
		Lack of integration between different	
		levels of health facilities	
		 Lack of defined reporting lines for 	
		surveillance data	
		 Different organization managing variou 	
		levels of health facilities in the district	
	Inadequate resources translate to poor	 Inadequate provision of facilities and 	
	disease surveillance	equipment	
		Lack of dedicated human resource for	
		surveillance	
		 Lack of financial support 	
		 Lack of dedicated line item for 	
		surveillance in provincial/district budge	
	In the current system surveillance is	 Hospital based surveillance 	
	predominantly passive	 Surveillance data collected from 	
		patients presenting to hospitals	
		Lack of human resource to conduct	
		surveillance in communities	
		Low level of surveillance activities	
		outside hospitals	

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Paper-based reporting is a key determinant	 Surveillance data compiled on hard
of delayed disease reporting	copies
	Hard copies are delivered from health
	facilities to district health office
	No dedicated human resource to
	transfer health facility reports to distric
	health office
Surveillance data is underutilized for	Monthly report submission by health
evidence-based decision making	facilities to district health office is
	mandatory
	No feedback provided from district
	health office to facilities on submitted
	reports
	 Submitted reports are not reviewed fo data errors
	 No one from district or provincial make
	monitoring visits to check fidelity of
	reported data
Lack of laboratory testing capacity takes a	There is no laboratory capable of
toll on disease surveillance	conducting tests for diseases under
	surveillance
	 Samples are sent to regional laboratory
	for testing
The lack of integration of the private sector	• At provincial or district level, no
in disease surveillance is a major gap	measures are taken to bring
	surveillance data from private health
	sector into mainstream
	Private health sector does not report
	surveillance data to district health offic
	or provincial health department except
	in case of COVID

- All study participants unanimously pointed out the lack of a comprehensive policy
 framework for disease surveillance. A respondent mentioned that despite that following
- 189 devolution in the health system where the province has the autonomy of decision making,
- ⁵⁹ 190 no initiative regarding disease surveillance policy has been taken. As a result, there is a lack

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of clarity in reporting disease-related data, coordination between different stakeholders,
and meaningful analysis of data and its use for taking action.

193 "National health policy emphasizes the importance of disease surveillance and having such a
194 system in place; however, it is up to provinces to develop detailed guidelines for disease

¹ 195 surveillance and ensure its implementation which is not happening! [Participant 14]."

4 196 Provincial disease surveillance and response unit

One of the study respondents mentioned that a digital information system named Provincial
 Disease Surveillance and Response Unit (PDSRU) was developed in 2016 with the support of
 donor money. The PDSRU had all the communicable diseases of importance listed and the
 system was expected to be linked up with secondary hospitals in the province for regular
 data collection. However, the PDSRU unit has remained dysfunctional and has not been
 utilized for the purpose it was built for.

203 "It is very unfortunate that we got the donor money to establish a surveillance system in the
 204 province, but we didn't plan for resources to make the system functional [participant 5]."

² 205 District health information system

One of the respondents said that the DHIS was developed and implemented in 2010 ⁶. It was meant to collate service delivery data from primary and secondary health facilities with a monthly reporting frequency. The data is collected on paper at the health facility level and a hard copy of the monthly DHIS reporting form is handed over physically by each facility to the district health office. There, a computer operator enters the data into the digital portal of DHIS which then can be viewed on a dashboard.

In the current state, DHIS is the only functional health information system that has up-todate disease information. But a study respondent pointed out that this information remains
underutilized for disease surveillance as there is hardly any review and feedback on the
reported data from higher levels (i.e., district health office or provincial health department).
Moreover, since the data is collated and shared at the end of each month, its utility for
detecting disease outbreaks is limited.

218 "DHIS data can be a very good source of passive surveillance, but we need to increase the
219 reporting frequency from monthly to weekly and have regular reviews of the reported data
220 [Participant 5]."

⁵ 221 Communicable Disease Control unit

A study respondent mentioned that for infectious diseases, a Communicable Disease Control (CDC) unit was established at the provincial level in 2015. The intent was to integrate all the vertical (disease-specific) programs under one roof for planning, resource allocation and public health interventions. Under the CDC unit, blood-borne diseases like HIV/AIDS, hepatitis C and hepatitis B could be looked after single-handedly when addressing the mode of spread, designing interventions and surveillance. Unfortunately, at the district level, the CDC unit lacks infrastructure (e.g., dedicated building and office space, computers, and internet), dedicated human resources (district focal CDC person) and a plan ensuring how the integration of various diseases can take place.

29 231 "Having CDC presents an immediate opportunity for syndromic surveillance; we should not
 31 232 waste this opportunity [Participant 10]."

Fragmentation in the healthcare system is a hindrance to a uniform reporting system

Under the public-private partnership (PPP), the public sector healthcare system in Thatta
 has been contracted out to various private providers. Under PPP, these providers are
 responsible for providing health services on a day-to-day basis while the health department
 provides a budget¹⁷.

One of the study respondents mentioned that in the Thatta district extensive contracting out of health services has been done and that each level of health facility (i.e., primary, and secondary) is managed by a different private partner. Distinct reporting lines and a lack of data-sharing mechanisms between private partners have given rise to fragmentation within the district health system.

"Primary level facilities are supposed to be linked with secondary level facilities for referrals and reporting of disease-related data, however, there are so many partners with each having its reporting line. This has negatively affected the reporting of disease surveillance [participant 10]."

A healthcare manager pointed out that in the Thatta district, surveillance for vaccine-preventable diseases (VPDs) is conducted by the district health office with the district surveillance coordinator as the focal point. Whereas notifiable diseases are reported by the focal persons of the disease-specific programs with a flow of information that is separate from that of VPDs. This vertical nature of surveillance of different diseases is inefficient in terms of resource utilization as it creates parallel systems where surveillance activities are carried out in siloes. These inefficiencies in turn create a weaker surveillance system and put the population at higher risk for communicable disease outbreaks.

255 "Every disease-specific program such as that of tuberculosis, malaria etc reports its data in
256 isolation, how can we have an integrated disease surveillance system in this situation?
257 [Participant 7]."

5 258 Inadequate resources translate to poor disease surveillance

A healthcare manager highlighted the dearth of human resource for surveillance in the district. He mentioned that in the district health office, there is only one person (district surveillance coordinator) who is tasked to coordinate for surveillance of vaccine-preventable diseases (VPDs), data reporting and data entry into DHIS for all eight public sector health facilities of the district. The increased workload results in delayed data entry and delay in data transfer to district health stakeholders. Not only that he lacks a team of dedicated individuals for surveillance, but he also has no provision of transportation for reaching out to health facilities and communities for active surveillance. Most of the time, he has to rely on making telephonic contact with each in charge of health facilities to get disease-related information.

All the study respondents mentioned that reporting for VPDs is mandatory and health
 facilities are required to send weekly reports (even for no cases called 'zero reports') of
 VPDs to the district surveillance coordinator. But due to a lack of resources e.g.,
 transportation and dedicated surveillance staff, the reports from various health facilities in
 the district often get delayed.

⁵⁶ 274 "Expecting one person to lead disease surveillance in the district, in the absence of
 ⁵⁷ 275 transportation and adequate human resource is too much to ask [Participant 2]."

1 2		
- 3 4	276	A district healthcare manager pointed out that for notifiable diseases, the district focal
5	277	persons of disease-specific programs have the responsibility of reporting data. The primary
6 7	278	role of the focal person is program implementation which involves numerous tasks from
8 9	279	planning and implementing to monitoring and reporting program activities. In absence of
10 11	280	adequate human resource, focal persons primarily rely on data reported as part of program
12 13	281	implementation. This has limitations namely 1) this is a form of passive surveillance rather
14 15	282	than active; 2) reporting of program data takes place at specific intervals whereas
16 17	283	surveillance requires continuous monitoring of disease cases and prompt action. Many
18	284	study respondents believed that these limitations lead to a disease surveillance system that
19 20	285	struggles with timely detection, and reporting of disease outbreaks.
21 22 23	286	In the current system, surveillance is predominantly passive
24 25	287	Study respondents pointed out that since the data collection is passive as it is collected
26 27	288	largely from those patients that present to health facilities, hence it is a form of passive
28 29 30	289	surveillance rather than active surveillance.
31 32	290	"We could be missing out on outbreaking at the community level since there is no one going
33 34	291	and actively screening the community members [Participant 1]"
35 36	292	Respondents attributed the lack of community-based active surveillance to the lack of
37 38	293	resources and mentioned that there is a need to increase resource allocation for
39 40	294	strengthening active surveillance.
41 42 43	295	
44 45	296	Paper-based reporting is a key determinant of delayed disease reporting
46 47	297	Several study respondents attributed the delayed reporting of surveillance data to paper-
48 49	298	based reporting. The system for reporting health-related data from health facilities to the
50 51	299	district health offices in Pakistan is paper-based for both VPDs and notifiable diseases. The
52 53	300	health facility in charge fills out a zero-reporting form (for VPDs) or a case report (for a
54	301	notifiable disease). A physical copy of this report is then sent to the district surveillance
55 56	302	officer. This often gets delayed as someone must visit the health facility or district
57 58 59 60	303	surveillance coordinator to deliver the physical copy of the report. To prevent delay,

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304 telephonic contact often plays a key role, however, it is not a feasible way to disseminate
305 the information to all the relevant stakeholders.
306 *"We should have a digital system with a dashboard which can show data in real time. We*307 *will avoid delayed reporting forever [participant 2]."*

308 Surveillance data is underutilized for evidence-based decision making

Most study respondents mentioned that data verification is essential to ensure its fidelity. To ensure data quality, monitoring and supervision of field staff and the facility healthcare staff sending data need strengthening. But all respondents agreed that in the existing system of disease surveillance, there is an emphasis on data collection only. No monitoring and supervision are happening from the district or provincial levels. Other than the circumstances where a suspected or confirmed case of disease under surveillance is reported, there is no action taken to verify the authenticity and quality of routinely reported

- ²⁷ 316 data.
- 317 "Despite that, the data is regularly collected through DHIS and other channels, it is rarely
 318 reviewed or utilized for analysis or action [Participant 12]."

³⁴ 319 Lack of laboratory testing capacity takes a toll on disease surveillance

All the study respondents showed their concern regarding poor laboratory capacity for surveillance in the district. Among the eight public sector health facilities in the Thatta district, only two have clinical laboratories. However, none of these laboratories is equipped to conduct testing for any of the VPDs or notifiable diseases in the district. Biological samples collected from suspected patients are sent to a regional laboratory that is based in the capital city of the country (laboratory at National Institute of Health, Islamabad) situated at least 1000 kilometres from Thatta district.

A healthcare manager pointed out that the absence of a fully equipped laboratory nearby calls for measures to ensure proper storage and transportation of biological samples. This not only is resource-intensive but adds to the delays in the system staggered by issues of delayed reporting.

331 "Provincial health department should, at the least, take measures to build a laboratory in the
 332 province so that disease surveillance can be made a little more efficient [Participant 6]."

333 The lack of integration of the private sector in disease surveillance is a major gap

All the study respondents considered the absence of private sector integration as an
important gap. The private health sector is a major stakeholder in service delivery and
caters to approximately 70% healthcare needs of the population. Unfortunately, however,
the service delivery data of the private health sector is not integrated into the DHIS of the
public health sector. In fact, the government is still lagging in taking measures to regulate
the private health sector in Sindh province.

One of the respondents said that integration of data from the private sector in the health
 information system is essential to ensure effective disease surveillance as currently, a
 significant chunk of the population's disease burden remains to be captured.

343 "Our disease surveillance will be at a loss from capturing the true disease burden unless it
344 integrates data from the private health sector [Participant 6]."

DISCUSSION

Our study explored multifaceted barriers to effective surveillance of communicable diseases in a rural district of Pakistan. Our study showed that the lack of policy guidelines at the provincial level was fundamental to ineffective disease surveillance and poor data reporting. Poor stakeholders' coordination led to a lack of sharing of surveillance data hampering the surveillance efforts. Due to poor resource planning, the digital information systems i.e., PDSRU and DHIS built using donor resources were underutilized. Having the district surveillance coordinator as the sole person responsible for surveillance activities in the district, in absence of additional resources, was considered a major resource gap by study respondents. Most study respondents were concerned about the predominantly passive nature of existing district surveillance. Paper-based reporting together with inadequate human resource was considered an important cause of delayed reporting in surveillance. The lack of laboratory testing capacity in the district was another determinant for delayed reporting. There was an increasing emphasis on collecting data than using it for predicting outbreaks or taking measures to control these. The absence of inclusion of infectious disease surveillance data of private sector data in the district surveillance was identified as another major gap by study respondents.

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> Despite that a decade has elapsed since the health system in Pakistan was devolved, the pace of provinces taking charge of health planning and resource generation has remained rather sluggish. A study respondent mentioned that despite the increasing infectious disease outbreaks in Sindh and other provinces in recent years i.e., measles, HIV/AIDS and the global COVID pandemic, initiatives regarding comprehensive guidelines and laws for disease surveillance are still lacking. Studies from Nigeria and Zambia show that the laws related to public health surveillance existed but were considered to be outdated and/or poorly implemented ¹⁸. Studies from Iran and Palestine concluded that having laws and policies for disease surveillance enable governments to allocate funds for establishing surveillance programs and that health authorities should play a lead role in ensuring their implementation ^{10 19}.

Having a dysfunctional PDSRU for reporting surveillance data is a classic example of relying on donor money instead of concentrating on building local capacity for a functional health information system. Many respondents termed this unfortunate and emphasized investing resources in reviving the PDSRU. In a study from China inadequacy of resources at the local level was identified as an important determinant of a functional digital information system for disease surveillance. The study reported that the top tier of government invests more in building digital information systems, but lower levels don't receive enough planned resources to ensure its implementation ²⁰. A functional digital information system has been found to speed up the reporting, improve data flow and ensure the availability of up-to-date data for the decision-makers. This eventually leads to early detection of and timely action against outbreaks ¹⁰.

Respondents in our study found the lack of adequate human resource for surveillance at the district level as concerning. Literature shows that for surveillance to be effective, adequate human resource is essential to undertake field-based surveillance and for efficient data reporting ²¹. The resource deficiencies including field-based staff have been shown to undermine effective disease surveillance ¹⁹²². Moreover, putting the burden of surveillance activities on healthcare staff engaged in service delivery negatively affects their motivation, performance, and consequently the quality of reporting ^{10 20 23}. Despite several advantages of contracting out of health services that the literature notes,

the structural challenges largely remain unaddressed ²⁴. One such challenge is poor

coordination between stakeholders. Many respondents pointed out that having multiple

stakeholders in the same district had been detrimental to disease surveillance due to a lack of coordination and ambiguous reporting lines. The flow of data is independent of the level of health facility defeating the notion of integrated disease surveillance. Poor coordination between stakeholders ^{21 22} and between different levels of health facilities ¹⁰ have been reported to adversely affect the data reporting for disease surveillance. Many study respondents pointed out the need to strengthen active surveillance in the district as in the present system, the surveillance was largely hospital-based where the data was being gathered from patients presenting to health facilities. Literature shows that the majority of people may opt not to show up for health seeking unless they develop serious symptoms ²⁰. This, in the event of a communicable disease, not only has the potential for the infection to spread but also leads to a delay in detecting an outbreak. Relying on passive surveillance only is often dependent on factors including patients' awareness, health-seeking behaviour and socioeconomic status and hence needs to be supplemented by some form of active surveillance ²³. Paper-based reporting in our study came out as an important barrier to timely reporting. The need for transitioning from slow, staff-reliant and paper-based reporting to the digital mode of reporting is increasingly recognized in literature ^{10 21}. A study from India has demonstrated improved disease notification and enhanced data reporting due to transitioning to digital media ²⁵. Except when suspected or a confirmed case of a disease is detected, data sent from health facilities is rarely reviewed at higher levels. Respondents in our study pointed out that there is more emphasis on data collection than its analysis and use. It is evident from the literature that providing regular feedback to facility staff on the data has been shown to act as a motivating factor and a performance boost ^{10 22}. Study respondents emphasized the need for having local laboratory capacity to ensure timely detection of disease outbreaks. Studies in literature have demonstrated that in absence of a local laboratory, rapid diagnostics kits (RDTs) may facilitate confirming outbreak until laboratory test results become available ²³ thus preventing delays that may incur in the transfer of biological samples ²². The extent to which a health system can detect disease outbreaks is dependent on its capacity to capture patients' data. In Pakistan, the private health sector caters to most of

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3 4	425	the population's healthcare needs. However, it is largely unregulated in Sindh province and
5 6	426	in Pakistan in general, leading to a lack of integration of its patient data with the public
7	427	sector. Studies show that the poor private sector engagement in disease surveillance is an
8 9	428	important issue hampering the surveillance efforts in many countries including India ^{22 25} ,
10 11	429	Iran ²⁶ and China ²³ .
12 13	430	LIMITATIONS OF THE STUDY
14 15	431	Our study was conducted in a predominantly rural district of Pakistan that is already
16 17	432	challenged in terms of resource availability. Hence, when generalizing the study findings,
18 19	433	these may be interpreted in a similar context. Due to the researchers' experience and
20	434	familiarity with the health system of the study district, the possibility of contamination of
21 22	435	study results with researchers' own perceptions can not be completely eliminated, however,
23 24	436	objectivity was ensured by note-taking during interviews and the use of interviews' audio
25 26	437	recordings to ensure accuracy in data reporting.
27 28	438	CONCLUSION
29 30	439	We concluded that poor governance was perceived to lead to underutilization of existing
31 32	440	resources for surveillance whereas lack of a policy framework on surveillance was
33 34	441	considered to lead to a poor investment of resources in surveillance infrastructure. The
35	442	absence of resources and inadequate human resource was identified by respondents as the
36 37	443	key determinant of delayed and inadequate reporting leading to delayed detection of
38 39	444	disease outbreaks. This was further aggravated by the absence of local laboratory capacity.
40 41	445	The existing surveillance system was perceived as largely paper-based, slow, and comprised
42 43	446	of hospital-based passive surveillance. The lack of private sector engagement in infectious
44 45	447	disease surveillance was perceived as a significant gap.
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50 51	450	RECOMMENDATIONS
52 53	451	The lack of directions from the provincial level regarding infectious disease surveillance
54 55	452	necessitates the need for formulation of policy guidelines outlining not just the technical
56	453	aspects of surveillance but also ensuring adequate resource planning and allocation to
57 58	454	establish and sustain effective infectious disease surveillance at the district level. To ensure
59 60	455	disease surveillance in the district, there is a need to i) address resource requirements

including adequate budget and human resource; ii) engage with the private health sector to capture maximum data of patients presenting to health facilities; iii) build active surveillance usigi ing to elin. i is instantly avai. into the existing system by having designated human resource, iv) take advantage of the paperless system for data reporting to eliminate reporting delays and make real-time reporting system where data is instantly available after collection.

1 2		
3 4	462	Funding
5 6	463	This work was supported by a grant from the World Health Organization grant number
7	464	1070479-0
8 9	465	Competing Interests
10 11	466	All authors declare that they have no competing interests
12 13	467	Authors contributions
14 15	468	IN, SS, RAS contributed to the plan and design of the study. IN developed the interview
16 17	469	guide which RAS & RH reviewed and provided feedback. IN led data collection and
18	470	performed data analysis. IN, SS, RAS & RH participated in the interpretation of the results. IN
19 20	471	drafted the manuscript. SS, RAS, and RH contributed to revisions of the manuscript for
21 22	472	intellectual content. All authors approved the final version of the manuscript.
23 24	473	Acknowledgement
25 26	474	We acknowledge all our participants for their cooperation during the conduct of this study
27 28	475	Checklist for the appropriate reporting statement
29 30	476	We used COnsolidated criteria for REporting Qualitative research (COREQ) checklist while
31	477	writing the manuscript to ensure rigour in reporting the data for qualitative research
32 33	478	Patient consent for publication
34 35	479	Not applicable
36 37	480	Data availability statement
38 39	481	All the data collected as part of this research study are reported in the manuscript
40 41	482	Word count: 4744
42	483	List of abbreviations
43 44	484	List of abbreviations
45 46	485	TB – Tuberculosis
47 48	486	DHIS – District health information system
49 50	487	PDSRU – Provincial Disease Surveillance and Response Unit
51 52	488	CDC – Communicable Disease Control
53	489	PPP – Public-private partnership
54 55	490	VPDs – Vaccine preventable diseases
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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

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Торіс	Item No.	Guide Questions/Description	Reported or Page No.		
Domain 1: Research team					
and reflexivity					
Personal characteristics					
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?			
Credentials	2	What were the researcher's credentials? E.g. PhD, MD			
Occupation	3	What was their occupation at the time of the study?			
Gender	4	Was the researcher male or female?			
Experience and training	5	What experience or training did the researcher have?			
Relationship with					
participants					
Relationship established	6	Was a relationship established prior to study commencement?			
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal			
the interviewer		goals, reasons for doing the research			
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?			
		e.g. Bias, assumptions, reasons and interests in the research topic			
Domain 2: Study design					
Theoretical framework					
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.			
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,			
		content analysis			
Participant selection					
Sampling	10	How were participants selected? e.g. purposive, convenience,			
		consecutive, snowball			
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,			
		email			
Sample size	12	How many participants were in the study?			
Non-participation	13	How many people refused to participate or dropped out? Reasons?			
Setting					
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace			
Presence of non-	15	Was anyone else present besides the participants and researchers?			
participants					
Description of sample	16	What are the important characteristics of the sample? e.g. demographic			
		data, date			
Data collection			-		
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?			
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?			
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?			
Field notes	20	Were field notes made during and/or after the inter view or focus group?			
Duration	20	What was the duration of the inter views or focus group?			
Data saturation	22	Was data saturation discussed?			
Transcripts returned	23	Were transcripts returned to participants for comment and/or	+		

Торіс	Item No.	Guide Questions/Description	Reported on
			Page No.
		correction?	
Domain 3: analysis and			•
findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding	25	Did authors provide a description of the coding tree?	
tree			
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			•
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?	
		Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	
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Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

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Exploring stakeholders' experiences and perceptions regarding barriers to effective surveillance of communicable diseases in a rural district of Pakistan – a qualitative study

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7 8	3	effective surveillance of communicable diseases in a rural district of Pakistan
8 9	4	– a qualitative study
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13 14	6	Imran Naeem ^{1*} , Sameen Siddiqi ² , Amna Rehana Siddiqui ³ , Rumina Hasan ⁴
15	7	
16 17		
18	8	¹ Assistant Professor, Community Health Sciences, Aga Khan University Karachi Pakistan
19 20	9	² Professor & Chair, Community Health Sciences, Aga Khan University Karachi Pakistan
21 22	10	³ Consultant, Community Health Sciences, Aga Khan University Karachi Pakistan
23 24	11	⁴ Professor, Pathology & Laboratory Medicine, Aga Khan University Karachi Pakistan
25	12	
26 27		
28	13	*Corresponding author
29 30	14	Email: Imran.naeem@aku.edu
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3 4	19	ABSTRACT
5 6	20	Objective: To explore the experiences and perceptions of health system stakeholders of a
7 8	21	rural district of Sindh, Pakistan regarding the barriers to effective surveillance of
9 10	22	communicable diseases.
10 11 12	23	Design: This qualitative descriptive exploratory design comprised in-depth interviews. Both
13	24	inductive and deductive thematic analysis was applied to identify key themes from the data.
14 15	25	Settings: The study was conducted in public sector healthcare facilities and the district
16 17	26	health office of the rural district of Thatta, in Sindh province, Pakistan.
18 19	27	Participants: Fifteen healthcare managers and healthcare providers working in the eight
20 21	28	public sector primary and secondary healthcare facilities were interviewed using an open-
22 23	29	ended in-depth interview guide.
24	30	Results: Key themes that emerged from the data were: poor governance and absence of
25 26	31	surveillance policy framework; fragmentation in the health system leading to lack of uniform
27 28	32	reporting; inadequate (human) resources that weakened the infrastructure for disease
29 30	33	surveillance; hospital-based reporting of cases that led to a predominantly passive
31 32	34	surveillance system; paper-based surveillance system as the key determinant of delayed
33 34	35	reporting; non-utilization of surveillance data for decision making; absence of local
35	36	laboratory capacity to complement the detection of disease outbreaks and lack of private
36 37	37	sector integration in disease surveillance.
38 39	38	Conclusions: Poor governance and lack of policy framework were perceived to be
40 41	39	responsible for weak surveillance infrastructure. Resource deficiencies including inadequate
42 43	40	human resource, paper-based reporting and the absence of local laboratory capacity were
44 45	41	considered to result in delayed, poor quality, and incomplete reporting. The lack of private
46	42	sector engagement was identified as a major gap.
47 48	43	
49 50	44	Konverder surveillance, communicable diseases, health convises research, qualitative, rural
51 52	44 45	Keywords: surveillance, communicable diseases, health services research, qualitative, rural, Pakistan
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46	Strengths and limitations of this study
47	• The study has explored experiences and perceptions regarding barriers to effective
48	surveillance of communicable diseases in-depth by involving representatives from
49	various levels of the healthcare system including from the public health sector and the
50	working under public-private partnership
51	• The inclusion of both healthcare managers and healthcare providers in the study
52	provided deeper insights into barriers at both the stewardship level and the operatior
53	level
54	• The study is amongst few in Pakistan to adopt a qualitative research approach for
55	exploring barriers to infectious disease surveillance as perceived and experienced by
56	health system stakeholders
57	• The study was conducted in a rural district of a developing country, hence study finding
58	should be interpreted in a similar context
59	

BACKGROUND

Infectious diseases continue to pose threat to the health of the public globally. In developing countries, infectious diseases form a significant portion of the disease burden including HIV/AIDS, tuberculosis (TB), malaria, respiratory infections, hepatitis B & C in adults and pneumonia and diarrhoea in children under five years of age ¹². In Pakistan, communicable diseases remain a major cause of public health concern with a significant contribution to morbidity and mortality. Conditions like overcrowding, low socio-economic status, poor hygiene and unsafe drinking water and poor awareness of health lead to an environment conducive to disease outbreaks. The Health System of the country is overwhelmed by issues of poor governance and lack of resources resulting in a surveillance system that is ill-equipped at detecting outbreaks of infectious disease ³. Before the devolution of the health system, Pakistan had two main sources to collect data for health indicators namely: 1) health management information system: this was designed to collect data on selected health indicators from health facilities with established reporting lines from provincial to federal health ministry; 2) data from vertical programs such as national TB control program, malaria control program, HIV/AIDS control program amongst others that also reported to federal health ministry ⁴. Following the health system devolution in 2010, administrative powers were devolved to provinces with the district becoming the autonomous unit for defining its health priorities and health planning ⁵. In the new, albeit ill-prepared administrative setup district health information system (DHIS) was established to collect disease-related data from the health facility level ⁶. In all provinces of the country including the Sindh province, DHIS is the only source of information on health indicators of the population based on service delivery data from public sector health facilities. However, the DHIS has remained underutilized for communicable disease surveillance. In the last five years, rural districts of Sindh have witnessed outbreaks of diseases such as measles ⁷ and HIV/AIDS⁸ while the surveillance system was unable to predict these outbreaks. As per the international health regulations, member states of the World Health Organization have the obligation to develop and strengthen disease surveillance with the help of existing health system resources ⁹. However, the emergence of recent outbreaks has indicated weaker surveillance of communicable diseases more so in rural areas of Pakistan. Moreover, only diseases with global priority (such as COVID-19 and Polio) have managed to get attention,

whereas surveillance for diseases of national priority has often struggled to compete for policy space and resources. The scientific literature on infectious disease surveillance in Pakistan is either quantitative in nature or mostly has discussed the implementation of models like the disease early warning system (DEWS) for surveillance ¹⁰⁻¹². However, there is a dearth of literature regarding the challenges that healthcare managers and providers face when implementing disease surveillance programs and perceptions and experiences of these healthcare professionals regarding barriers to effective surveillance of infectious diseases are less well studied in Pakistan. Such information will not only give an in-depth insight into the challenges faced in infectious disease surveillance but also inform the policy makers with recommendations for addressing those challenges. Hence, we conducted this study to explore the experiences and perceptions of health system stakeholders of a rural district of Sindh, Pakistan regarding the barriers to effective surveillance of communicable diseases.

METHODS

105 Study design and setting

This study used a qualitative descriptive exploratory design to explore the perceptions and experiences of district health system stakeholders regarding the barriers to an effective surveillance system for communicable diseases in the rural district of Thatta located in the province of Sindh, Pakistan. Thatta is situated approximately 100 kilometres from the provincial capital of Karachi. It is a predominantly rural district with an approximate population of 1 million ^{13 14}. Health indicators including maternal mortality ratio and neonatal mortality rate are amongst the worst in the country ¹⁵¹⁶. The situation of the healthcare system of Thatta is comparable to any other rural district of Pakistan with inadequate infrastructure and resources. There exist primary and secondary healthcare facilities in the district and there is also a private healthcare system in the district comprising general practitioner clinics and small hospitals. The study was conducted from February 15 to April 30, 2022, in eight public sector primary and secondary healthcare facilities in the district.

119 Study participants

We used purposive sampling to select study participants. Eligible participants were healthcare managers and healthcare providers working in the eight public sector primary and secondary healthcare facilities. Healthcare managers were those working at the district level and were responsible for the management of health services. Healthcare providers were the doctors responsible for the provision of clinical care at selected healthcare facilities. Participants included both males (n = 12) and females (n = 3). The age range of study participants was 29 – 57 years. The experience of study participants with the district health system ranged from 5 - 30 years.

We used the 'saturation principle' to determine the sample size for the study. Upon researchers' observation, with further interviews yielding no new or significant findings, data collection was stopped. This resulted in 15 in-depth interviews with healthcare managers and healthcare providers.

132 Data collection

The data were collected using an open-ended interview guide. The guide comprised questions and probes regarding perceptions and experiences about the current state of communicable disease surveillance and challenges in infrastructure and financing for surveillance, barriers in data reporting, timeliness of reporting, and quality of reported data. The guide was developed following a thorough literature review and the researchers' own experience and expertise on the subject. The guide was piloted before data collection. Based on the pretest results, researchers gained new insights and revised the interview guide by adding further questions and probes. The interviews were conducted by the first author (IN) having research experience in health systems, communicable diseases, and qualitative research. The first author moderated the interviews along with note-takers. The interviews were conducted in the local language (Sindhi) and were audiotaped. A debriefing session was held after each interview to reflect on the participants' responses. The interviews took place in health facilities at a time suitable for study participants with each interview lasting about 40 – 50 minutes.

²⁵ 147 **Researchers' reflexivity**

In qualitative research, research findings are liable to be influenced by researchers' interest
 and understanding of the topic. In this study, researchers were not the staff of the health

facilities where the study was conducted. However, due to the research team's four years of work experience in the district, they were not considered outsiders by the study respondents but rather someone familiar with the district health system and interested in exploring their views. Moreover, researchers used reflexive notes during data collection that fed into the interpretation of study findings to minimize researcher bias. Researchers had knowledge of the health system and infectious diseases research which influenced the development of the interview guide, however, while pre-testing the guide researchers gained new knowledge which informed the revision of the interview guide. Patient and public involvement statement Patients or the public were not involved in the design, or conduct, or reporting, or dissemination plans of our research DATA ANALYSIS We used both inductive and deductive methods to perform data analysis. The analysis approach used a combination of interviews with study participants facilitated by field observations. Researchers' background knowledge of health systems and infectious disease research guided the process of data collection and analysis using the deductive method. However, during the analysis new themes emerged that were analysed using the inductive method. All audio tapes were transcribed from Sindhi to English and interview notes were written. Manual content analysis was performed where interview notes and notes from audio transcripts were read and re-read to identify patterns in data. Manual codes were assigned to identified patterns in data which were subsequently grouped and classified into main themes. All the authors and field team members read the themes, and discrepancies were discussed during the interpretation and analysis of data. The themes emerging from the analysis were shared and discussed with study participants for their comments. RESULTS Data analysis identified a number of core themes from in-depth interviews. Where appropriate, direct quotes from the interviews have been used to ensure rigour in the data reporting. To avoid identifying specific individuals, the participants have been allocated aliases. Table 1 summarizes the themes and codes that emerged from the data.

Themes	Codes
The absence of a surveillance policy	Lack of provincial policy on infectious
framework and poor governance leads to	disease surveillance
an ill-defined disease surveillance system	Lack of laws
	Lack of surveillance standards
	• Lack of resource planning leading to
	dysfunctional digital information
	systems
	 Lack of planning to ensure integrated
	surveillance of infectious diseases
Fragmentation in the healthcare system is a	Poor coordination between health
hindrance to a uniform reporting system	system stakeholders
	Lack of integration between different
	levels of health facilities
	• Lack of defined reporting lines for
	surveillance data
	• Different organizations managing
	various levels of health facilities in the
	district
Inadequate resources translate to poor	 Inadequate provision of facilities and
disease surveillance	equipment
	• Lack of dedicated human resource for
	surveillance
	Lack of financial support
	• Lack of dedicated line item for
	surveillance in provincial/district budg
In the current system surveillance is	Hospital-based surveillance
predominantly passive	Surveillance data collected from
	patients presenting to hospitals
	• Lack of human resource to conduct
	surveillance in communities
	• Low level of surveillance activities
	outside hospitals
Paper-based reporting is a key determinant	Surveillance data compiled on hard
of delayed disease reporting	copies
	• Hard copies are delivered from health
	facilities to the district health office

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	 No dedicated human resource to transfer health facility reports to the district health office 	
Surveillance data is underutilized for evidence-based decision making	 Monthly report submission by health facilities to the district health office is mandatory No feedback was provided from the district health office to facilities on submitted reports Submitted reports are not reviewed for data errors No one from the district or provincial makes monitoring visits to check the fidelity of reported data 	
Lack of laboratory testing capacity takes a toll on disease surveillance	 There is no laboratory capable of conducting tests for diseases under surveillance Samples are sent to a regional laboratory for testing 	
The lack of integration of the private sector in disease surveillance is a major gap	 At the provincial or district level, no measures are taken to bring surveillance data from the private health sector into the mainstream The private health sector does not report surveillance data to the district health office or provincial health department except in case of COVID 	
The absence of a surveillance policy framew	ork and poor governance leads to an ill-	
defined disease surveillance system		
All study participants unanimously pointed out the lack of a comprehensive policy framework for disease surveillance. A respondent mentioned that despite that following		
devolution in the health system where the pr	· · · ·	
no initiative regarding disease surveillance po	olicy has been taken. As a result, there is a lac	
of clarity in reporting disease-related data, co	oordination between different stakeholders,	
and meaningful analysis of data and its use for	or taking action.	

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3 4	190	"National health policy emphasizes the importance of disease surveillance and having such a
5 6	191	system in place; however, it is up to provinces to develop detailed guidelines for disease
0 7 8	192	surveillance and ensure its implementation which is not happening! [Participant 14]."
9 10 11	193	Provincial disease surveillance and response unit
12	194	One of the study respondents mentioned that a digital information system named Provincial
13 14	195	Disease Surveillance and Response Unit (PDSRU) was developed in 2016 with the support of
15 16	196	donor money. The PDSRU had all the communicable diseases of importance listed and the
17 18	197	system was expected to be linked up with secondary hospitals in the province for regular
19 20	198	data collection. However, the PDSRU unit has remained dysfunctional and has not been
21 22	199	utilized for the purpose it was built for.
23	200	"It is very unfortunate that we got the donor money to establish a surveillance system in the
24 25	200	province, but we didn't plan for resources to make the system functional [participant 5]."
26 27	201	
28 29	202	District health information system
30 31	203	One of the respondents said that the DHIS was developed and implemented in 2010 ⁶ . It was
32 33	204	meant to collate service delivery data from primary and secondary health facilities with a
34 35	205	monthly reporting frequency. The data is collected on paper at the health facility level and a
36	206	hard copy of the monthly DHIS reporting form is handed over physically by each facility to
37 38	207	the district health office. There, a computer operator enters the data into the digital portal
39 40	208	of DHIS which then can be viewed on a dashboard.
41 42 42	209	In its current state, DHIS is the only functional health information system that has up-to-
43 44	210	date disease information. But a study respondent pointed out that this information remains
45 46	211	underutilized for disease surveillance as there is hardly any review and feedback on the
47 48	212	reported data from higher levels (i.e., district health office or provincial health department).
49 50	213	Moreover, since the data is collated and shared at the end of each month, its utility for
51 52	214	detecting disease outbreaks is limited.
53 54	215	"DHIS data can be a very good source of passive surveillance, but we need to increase the
55 56	216	reporting frequency from monthly to weekly and have regular reviews of the reported data
57 58	217	[Participant 5]."
59 60	218	Communicable Disease Control unit

A study respondent mentioned that for infectious diseases, a Communicable Disease Control (CDC) unit was established at the provincial level in 2015. The intent was to integrate all the vertical (disease-specific) programs under one roof for planning, resource allocation and public health interventions. Under the CDC unit, blood-borne diseases like HIV/AIDS, hepatitis C and hepatitis B could be looked after single-handedly when addressing the mode of spread, designing interventions and surveillance. Unfortunately, at the district level, the CDC unit lacks infrastructure (e.g., dedicated building and office space, computers, and internet), dedicated human resources (district focal CDC person) and a plan ensuring how the integration of various diseases can take place. "Having CDC presents an immediate opportunity for syndromic surveillance; we should not waste this opportunity [Participant 10]."

Under the public-private partnership (PPP), the public sector healthcare system in Thatta has been contracted out to various private providers. Under PPP, these providers are responsible for providing health services on a day-to-day basis while the health department provides a budget¹⁷.

Fragmentation in the healthcare system is a hindrance to a uniform reporting system

One of the study respondents mentioned that in the Thatta district extensive contracting out of health services has been done and that each level of health facility (i.e., primary, and secondary) is managed by a different private partner. Distinct reporting lines and a lack of data-sharing mechanisms between private partners have given rise to fragmentation within the district health system.

45 240 "Primary level facilities are supposed to be linked with secondary level facilities for referrals
 46 47 241 and reporting of disease-related data, however, there are so many partners with each
 48 242 having its reporting line. This has negatively affected the reporting of disease surveillance
 50 51 243 [participant 10]."

A healthcare manager pointed out that in the Thatta district, surveillance for vaccine-preventable diseases (VPDs) is conducted by the district health office with the district surveillance coordinator as the focal point. Whereas notifiable diseases are reported by the focal persons of the disease-specific programs with a flow of information that is separate

from that of VPDs. This vertical nature of surveillance of different diseases is inefficient in
terms of resource utilization as it creates parallel systems where surveillance activities are
carried out in siloes. These inefficiencies in turn create a weaker surveillance system and put
the population at higher risk for communicable disease outbreaks.

252 "Every disease-specific program such as that of tuberculosis, malaria etc reports its data in
253 isolation, how can we have an integrated disease surveillance system in this situation?
254 [Participant 7]."

² 255 Inadequate resources translate to poor disease surveillance

A healthcare manager highlighted the dearth of human resource for surveillance in the district. He mentioned that in the district health office, there is only one person (district surveillance coordinator) who is tasked to coordinate for surveillance of vaccine-preventable diseases (VPDs), data reporting and data entry into DHIS for all eight public sector health facilities of the district. The increased workload results in delayed data entry and delay in data transfer to district health stakeholders. Not only that he lacks a team of dedicated individuals for surveillance, but he also has no provision of transportation for reaching out to health facilities and communities for active surveillance. Most of the time, he has to rely on making telephone contact with each in charge of health facilities to get disease-related information.

All the study respondents mentioned that reporting for VPDs is mandatory and health facilities are required to send weekly reports (even for no cases called 'zero reports') of VPDs to the district surveillance coordinator. But due to a lack of resources e.g., transportation and dedicated surveillance staff, the reports from various health facilities in the district often get delayed.

⁴⁹ 271 *"Expecting one person to lead disease surveillance in the district, in the absence of* ⁵⁰ 272 *transportation and adequate human resource is too much to ask [Participant 2]."*

A district healthcare manager pointed out that for notifiable diseases, the district focal
 persons of disease-specific programs have the responsibility of reporting data. The primary
 role of the focal person is program implementation which involves numerous tasks from
 planning and implementing to monitoring and reporting program activities. In absence of

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3 4	277	adequate human resource, focal persons primarily rely on data reported as part of program
5 6	278	implementation. This has limitations namely 1) this is a form of passive surveillance rather
7	279	than active; 2) reporting of program data takes place at specific intervals whereas
8 9	280	surveillance requires continuous monitoring of disease cases and prompt action. Many
10 11	281	study respondents believed that these limitations lead to a disease surveillance system that
12 13	282	struggles with the timely detection, and reporting of disease outbreaks.
14 15 16	283	In the current system, surveillance is predominantly passive
17 18	284	Study respondents pointed out that since the data collection is passive as it is collected
19 20	285	largely from those patients that present to health facilities, hence it is a form of passive
21 22	286	surveillance rather than active surveillance.
23 24	287	"We could be missing out on outbreaking at the community level since there is no one going
25 26	288	and actively screening the community members [Participant 1]"
27 28 29	289	Respondents attributed the lack of community-based active surveillance to the lack of
30	290	resources and mentioned that there is a need to increase resource allocation for
31 32 33	291	strengthening active surveillance.
33 34 35	292	
36 37 38	293	Paper-based reporting is a key determinant of delayed disease reporting
39 40	294	Several study respondents attributed the delayed reporting of surveillance data to paper-
41 42	295	based reporting. The system for reporting health-related data from health facilities to the
43	296	district health offices in Pakistan is paper-based for both VPDs and notifiable diseases. The
44 45	297	health facility in charge fills out a zero-reporting form (for VPDs) or a case report (for a
46 47	298	notifiable disease). A physical copy of this report is then sent to the district surveillance
48 49	299	officer. This often gets delayed as someone must visit the health facility or district
50 51	300	surveillance coordinator to deliver the physical copy of the report. To prevent delay,
52 53	301	telephonic contact often plays a key role, however, it is not a feasible way to disseminate
53 54 55	302	the information to all the relevant stakeholders.
56 57	303	"We should have a digital system with a dashboard which can show data in real-time. We
58 59 60	304	will avoid delayed reporting forever [participant 2]."

1 2 3		
4 5	305	Surveillance data is underutilized for evidence-based decision making
6	306	Most study respondents mentioned that data verification is essential to ensure its fidelity.
7 8	307	To ensure data quality, monitoring and supervision of field staff and the facility healthcare
9 10	308	staff sending data need strengthening. But all respondents agreed that in the existing
11 12	309	system of disease surveillance, there is an emphasis on data collection only. No monitoring
13 14	310	and supervision are happening from the district or provincial levels. Other than the
15	311	circumstances where a suspected or confirmed case of disease under surveillance is
16 17	312	reported, there is no action taken to verify the authenticity and quality of routinely reported
18 19	313	data.
20 21	314	"Despite that, the data is regularly collected through DHIS and other channels, it is rarely
22 23	315	reviewed or utilized for analysis or action [Participant 12]."
24	515	
25 26	316	Lack of laboratory testing capacity takes a toll on disease surveillance
27 28	317	All the study respondents showed their concern regarding poor laboratory capacity for
29 30	318	surveillance in the district. Among the eight public sector health facilities in the Thatta
31 32	319	district, only two have clinical laboratories. However, none of these laboratories is equipped
33 34	320	to conduct testing for any of the VPDs or notifiable diseases in the district. Biological
35 36	321	samples collected from suspected patients are sent to a regional laboratory that is based in
37	322	the capital city of the country (laboratory at National Institute of Health, Islamabad) situated
38 39 40	323	at least 1000 kilometres from Thatta district.
41 42	324	A healthcare manager pointed out that the absence of a fully equipped laboratory nearby
43 44	325	calls for measures to ensure proper storage and transportation of biological samples. This
45 46	326	not only is resource-intensive but adds to the delays in the system staggered by issues of
47 48	327	delayed reporting.
49 50	328	"Provincial health department should, at the least, take measures to build a laboratory in the
51 52	329	province so that disease surveillance can be made a little more efficient [Participant 6]."
53 54 55	330	The lack of integration of the private sector in disease surveillance is a major gap
56 57	331	All the study respondents considered the absence of private-sector integration as an
58	332	important gap. The private health sector is a major stakeholder in service delivery and
59 60	333	caters to approximately 70% healthcare needs of the population. Unfortunately, however,

the service delivery data of the private health sector is not integrated into the DHIS of the
public health sector. In fact, the government is still lagging in taking measures to regulate
the private health sector in Sindh province.

One of the respondents said that integration of data from the private sector in the health
information system is essential to ensure effective disease surveillance as currently, a
significant chunk of the population's disease burden remains to be captured.

340 "Our disease surveillance will be at a loss from capturing the true disease burden unless it
341 integrates data from the private health sector [Participant 6]."

DISCUSSION

Our study explored multifaceted barriers to effective surveillance of communicable diseases in a rural district of Pakistan. Our study showed that the lack of policy guidelines at the provincial level was fundamental to ineffective disease surveillance and poor data reporting. Poor stakeholders' coordination led to a lack of sharing of surveillance data hampering the surveillance efforts. Due to poor resource planning, the digital information systems i.e., PDSRU and DHIS built using donor resources were underutilized. Having the district surveillance coordinator as the sole person responsible for surveillance activities in the district, in absence of additional resources, was considered a major resource gap by study respondents. Most study respondents were concerned about the predominantly passive nature of existing district surveillance. Paper-based reporting together with inadequate human resource was considered an important cause of delayed reporting in surveillance. The lack of laboratory testing capacity in the district was another determinant for delayed reporting. There was an increasing emphasis on collecting data than using it for predicting outbreaks or taking measures to control these. The absence of inclusion of infectious disease surveillance data of private sector data in the district surveillance was identified as another major gap by study respondents.

Despite that a decade has elapsed since the health system in Pakistan was devolved, the
 pace of provinces taking charge of health planning and resource generation has remained
 rather sluggish. A study respondent mentioned that despite the increasing infectious
 disease outbreaks in Sindh and other provinces in recent years i.e., measles, HIV/AIDS and
 the global COVID pandemic, initiatives regarding comprehensive guidelines and laws for

disease surveillance are still lacking. Studies from Nigeria and Zambia show that the laws
 related to public health surveillance existed but were considered to be outdated and/or
 poorly implemented ¹⁸. Studies from Iran and Palestine concluded that having laws and
 policies for disease surveillance enable governments to allocate funds for establishing
 surveillance programs and that health authorities should play a lead role in ensuring their
 implementation ^{10 19}.

Having a dysfunctional PDSRU for reporting surveillance data is a classic example of relying on donor money instead of concentrating on building local capacity for a functional health information system. Many respondents termed this unfortunate and emphasized investing resources in reviving the PDSRU. In a study from China inadequacy of resources at the local level was identified as an important determinant of a functional digital information system for disease surveillance. The study reported that the top tier of government invests more in building digital information systems, but lower levels don't receive enough planned resources to ensure its implementation ²⁰. A functional digital information system has been found to speed up the reporting, improve data flow and ensure the availability of up-to-date data for the decision-makers. This eventually leads to early detection of and timely action against outbreaks ¹⁰.

Respondents in our study found the lack of adequate human resource for surveillance at the district level as concerning. Literature shows that for surveillance to be effective, adequate human resource is essential to undertake field-based surveillance and for efficient data reporting ²¹. The resource deficiencies including field-based staff have been shown to undermine effective disease surveillance ¹⁹²². Moreover, putting the burden of surveillance activities on healthcare staff engaged in service delivery negatively affects their motivation, performance, and consequently the quality of reporting ^{10 20 23}.

47 388 Despite several advantages of contracting out health services that the literature notes, the
 48 389 structural challenges largely remain unaddressed ²⁴. One such challenge is poor
 50

coordination between stakeholders. Many respondents pointed out that having multiple stakeholders in the same district had been detrimental to disease surveillance due to a lack of coordination and ambiguous reporting lines. The flow of data is independent of the level of health facility defeating the notion of integrated disease surveillance. Poor coordination between stakeholders ^{21 22} and between different levels of health facilities ¹⁰ have been reported to adversely affect the data reporting for disease surveillance.

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Many study respondents pointed out the need to strengthen active surveillance in the district as in the present system, the surveillance was largely hospital-based where the data was being gathered from patients presenting to health facilities. Literature shows that the majority of people may opt not to show up for health seeking unless they develop serious symptoms ²⁰. This, in the event of a communicable disease, not only has the potential for the infection to spread but also leads to a delay in detecting an outbreak. Relying on passive surveillance only is often dependent on factors including patients' awareness, health-seeking behaviour and socioeconomic status and hence needs to be supplemented by some form of active surveillance ²³. Paper-based reporting in our study came out as an important barrier to timely reporting. The need for transitioning from slow, staff-reliant and paper-based reporting to the digital mode of reporting is increasingly recognized in literature ^{10 21}. A study from India has demonstrated improved disease notification and enhanced data reporting due to transitioning to digital media²⁵. Except when a suspected or confirmed case of a disease is detected, data sent from health facilities is rarely reviewed at higher levels. Respondents in our study pointed out that there is more emphasis on data collection than its analysis and use. It is evident from the literature that providing regular feedback to facility staff on the data has been shown to act as a motivating factor and a performance boost ^{10 22}. Study respondents emphasized the need for having local laboratory capacity to ensure the timely detection of disease outbreaks. Studies in literature have demonstrated that in absence of a local laboratory, rapid diagnostics kits (RDTs) may facilitate confirming outbreak until laboratory test results become available ²³ thus preventing delays that may incur in the transfer of biological samples ²². The extent to which a health system can detect disease outbreaks is dependent on its capacity to capture patients' data. In Pakistan, the private health sector caters to most of

the population's healthcare needs. However, it is largely unregulated in Sindh province and

sector. Studies show that the poor private sector engagement in disease surveillance is an

important issue hampering the surveillance efforts in many countries including India ^{22 25},

in Pakistan in general, leading to a lack of integration of its patient data with the public

Iran ²⁶ and China ²³.

1 2		
3 4	427	LIMITATIONS OF THE STUDY
5 6	428	Our study was conducted in a predominantly rural district of Pakistan that is already
7 8	429	challenged in terms of resource availability. Hence, when generalizing the study findings,
9 10	430	these may be interpreted in a similar context. Due to the researchers' experience and
11	431	familiarity with the health system of the study district, the possibility of contamination of
12 13	432	study results with researchers' own perceptions cannot be completely eliminated, however,
14 15	433	objectivity was ensured by note-taking during interviews and the use of interviews' audio
16 17	434	recordings to ensure accuracy in data reporting.
18 19	435	RECOMMENDATIONS
20 21	436	The lack of directions from the provincial level regarding infectious disease surveillance
22 23	437	necessitates the need for formulation of policy guidelines outlining not just the technical
24	438	aspects of surveillance but also ensuring adequate resource planning and allocation to
25 26	439	establish and sustain effective infectious disease surveillance at the district level. To ensure
27 28	440	disease surveillance in the district, there is a need to i) address resource requirements
29 30	441	including adequate budget and human resource; ii) engage with the private health sector to
31 32	442	capture maximum data of patients presenting to health facilities; iii) build active surveillance
33 34	443	into the existing system by having designated human resource, iv) take advantage of the
35 36	444	paperless system for data reporting to eliminate reporting delays and make real-time
37	445	reporting system where data is instantly available after collection.
38 39	446	
40 41	447	CONCLUSION
42 43	448	We concluded that poor governance was perceived to lead to underutilization of existing
44 45	449	resources for surveillance whereas lack of a policy framework on surveillance was
46 47	450	considered to lead to a poor investment of resources in surveillance infrastructure. The
48 49	451	absence of resources and inadequate human resource was identified by respondents as the
50 51	452	key determinant of delayed and inadequate reporting leading to delayed detection of
52	453	disease outbreaks. This was further aggravated by the absence of local laboratory capacity.
53 54	454	The existing surveillance system was perceived as largely paper-based, slow, and comprised
55 56	455	of hospital-based passive surveillance. The lack of private sector engagement in infectious
57 58	456	disease surveillance was perceived as a significant gap.
59 60	457	

1 2		
- 3 4	458	Funding
5	459	This work was supported by a grant from the World Health Organization grant number
6 7	460	1070479-0
8 9	461	Competing Interests
10 11	462	All authors declare that they have no competing interests
12 13	463	Authors contributions
14 15	464	IN, SS, RAS contributed to the plan and design of the study. IN developed the interview
16	465	guide which RAS & RH reviewed and provided feedback. IN led data collection and
17 18	466	performed data analysis. IN, SS, RAS & RH participated in the interpretation of the results. IN
19 20	467	drafted the manuscript. SS, RAS, and RH contributed to revisions of the manuscript for
21 22	468	intellectual content. All authors approved the final version of the manuscript.
23 24	469	Acknowledgement
25 26	470	We acknowledge all our participants for their cooperation during the conduct of this study
27	471	Checklist for the appropriate reporting statement
28 29	472	We used COnsolidated criteria for REporting Qualitative research (COREQ) checklist while
30 31	473	writing the manuscript to ensure rigour in reporting the data for qualitative research
32 33	474	Patient consent for publication
34 35	475	Not applicable
36 37	476	Data availability statement
38	477	All the data collected as part of this research study are reported in the manuscript
39 40	478	Word count: 5057
41 42	479	Word count: 5057 List of abbreviations TB – Tuberculosis
43 44	480	TB – Tuberculosis
45 46	481	DHIS – District health information system
47 48	482	PDSRU – Provincial Disease Surveillance and Response Unit
49	483	CDC – Communicable Disease Control
50 51	484	PPP – Public-private partnership
52 53	485	VPDs – Vaccine preventable diseases
54 55	486	Research Ethics Approval
56 57	487	This study involves human participants and was approved by the ethics review committee of
58 59	488	the Aga Khan University Karachi Pakistan (reference # ERC # 2020-5777-15184). Participants
59 60	489	gave informed consent to participate in the study before taking part.

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript

where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript

accordingly before submitting or note N/A.

			Page No			
Domain 1: Research team			-			
and reflexivity						
Personal characteristics						
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?				
Credentials	2	What were the researcher's credentials? E.g. PhD, MD				
Occupation	3	What was their occupation at the time of the study?				
Gender	4	Was the researcher male or female?				
Experience and training	5	What experience or training did the researcher have?				
Relationship with						
participants		A				
Relationship established	6	Was a relationship established prior to study commencement?				
Participant knowledge of	7	What did the participants know about the researcher? e.g. personal				
the interviewer		goals, reasons for doing the research				
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator?				
		e.g. Bias, assumptions, reasons and interests in the research topic				
Domain 2: Study design	•					
Theoretical framework						
Methodological orientation	9	What methodological orientation was stated to underpin the study? e.g.				
and Theory		grounded theory, discourse analysis, ethnography, phenomenology,				
		content analysis				
Participant selection						
Sampling 10 How were participants selected? e.g. purposive, convenience,						
		consecutive, snowball				
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail,				
		email				
Sample size	12	How many participants were in the study?				
Non-participation	13	How many people refused to participate or dropped out? Reasons?				
Setting			1			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace				
Presence of non-	15	Was anyone else present besides the participants and researchers?				
participants		,				
Description of sample	16	What are the important characteristics of the sample? e.g. demographic				
- I		data, date				
Data collection	1	· · ·	1			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot				
		tested?				
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?				
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?				
Field notes	20	Were field notes made during and/or after the inter view or focus group?				
Duration	20	What was the duration of the inter views or focus group?				
Data saturation	21	What was the duration of the inter views of focus group? Was data saturation discussed?				
Transcripts returned	22	Were transcripts returned to participants for comment and/or	<u> </u>			

Page	24	of	23
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Торіс	Item No.	Guide Questions/Description	Reported or			
			Page No.			
		correction?				
Domain 3: analysis and						
findings						
Data analysis						
Number of data coders	24	How many data coders coded the data?				
Description of the coding	25	Did authors provide a description of the coding tree?				
tree						
Derivation of themes	26	Were themes identified in advance or derived from the data?				
Software	27	What software, if applicable, was used to manage the data?				
Participant checking	28	Did participants provide feedback on the findings?				
Reporting						
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings?				
		Was each quotation identified? e.g. participant number				
Data and findings consistent	30	Was there consistency between the data presented and the findings?				
Clarity of major themes	31	Were major themes clearly presented in the findings?				
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?				

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

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