

# An evaluation of Mongolia's universal patient-held health booklets as a tool for continuity of care in chronic disease patients: a cross-sectional study

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**An evaluation of Mongolia's universal patient-held health booklets as a tool for continuity of care in chronic disease patients: a cross-sectional study**

**Can universal patient-held booklets promote continuity of care and patient-centred care in low resource countries? The case of Mongolia.**

**Hussein Ibrahim, Uyanga Munkhbayar, Claire Humphries, Chimedsuren Ochir, Aira Toivgoo, Indermohan Narula, Richard Lilford, Semira Manaseki-Holland**

Institute of Applied Health Research, College of Medical and Dental Sciences,  
University of Birmingham, Birmingham, B15 2TT, United Kingdom

Hussein Ibrahim  
International Health BMedSc

School of Public Health, Mongolian National University of Medical Sciences, Jamyang  
Street 3, Ulaanbaatar, Mongolia

Uyanga Munkhbayar  
Public Health MSc

Institute of Applied Health Research, College of Medical and Dental Sciences,  
University of Birmingham, Birmingham, B15 2TT, United Kingdom

Claire Humphries  
International Public Health PhD

School of Public Health, Mongolian National University of Medical Sciences, Jamyang  
Street 3, Ulaanbaatar, Mongolia

Chimedsuren Ochir  
Dean of School of Public Health

Wellspring NGO, 2F Zorig Foundation Building, Peace Avenue 9A, Ulaanbaatar,  
Mongolia

Aira Toivgoo  
Executive Officer

Wellspring NGO, 2F Zorig Foundation Building, Peace Avenue 9A, Ulaanbaatar,  
Mongolia

Indermohan S Narula  
Adjunct Professor

Institute of Applied Health Research, College of Medical and Dental Sciences,  
University of Birmingham, Birmingham, B15 2TT, United Kingdom

Semira Manaseki-Holland  
Clinical Senior Lecturer

Correspondence to: Semira Manaseki-Holland  
Institute of Applied Health Research, College of  
Medical and Dental Sciences, University of  
Birmingham, Birmingham, B15 2TT, United  
Kingdom  
[s.manasekiholland@bham.ac.uk](mailto:s.manasekiholland@bham.ac.uk)

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## ABSTRACT

**Objective:** To describe a nationwide Patient-held Health Booklet system and investigate its use and completeness for clinical information transfer during chronic non-communicable disease (NCD) outpatient visits in Mongolia.

**Design:** Cross-sectional survey and document review.

**Setting:** Two large government secondary-care hospital outpatient departments (OPD) in Ulaanbaatar.

**Participants:** 395 adult outpatients attending for NCDs.

**Outcome measure:** Numbers of patient-held records brought and used by OPD doctors; Completeness of records on arrival and leaving OPD.

**Results:** 96% (379) brought handover documentation from previous provider/s: 94% had patient-held health Booklets, 27% other additional documents and 4% had nothing. 67% were referred from primary-care and 44% referred back for follow-up. On leaving the OPD, 93% were provided with written clinical information in the Booklet and 39% were also given other documents. 84% recalled being given verbal information. Only 40.8% of the records of the OPD consultation with written information included all three key handover information items (diagnosis, management/treatment and follow-up). The Booklets were the best completed type of document, with evidence that they were consulted by patients (80%), public (95%) and private (77%) providers. Living >1 hour away (OR=0.28; 95%CI 0.13, 0.61) decreased the

likelihood of receiving written management/treatment information; living >1 hour away (OR=0.48; 95%CI 0.27, 0.87), comorbidity (OR=0.55; 95%CI 0.35, 0.87), and returning to secondary-care for follow-up (OR=0.52; 95%CI 0.33, 0.80) all independently decreased the likelihood of receiving written follow-up information. A Ministry order mandates the use of the patient-held health Booklet, but there were no other policies, guidelines or clinician training relating to their use.

**Conclusions:** The universal Patient-Held Health Booklets were well-accepted, well-utilised and the best completed handover documentation. The Booklets provided a successful handover option for chronic NCD patients in Mongolia but their completeness needs improving. There is potential for their application globally.

## STRENGTHS AND LIMITATIONS OF THIS STUDY

### Strengths:

- Reduction of recall bias by interviewing patients immediately before and after the clinic consultation.
- Sample from Ulaanbaatar, an area which accommodates 1.1 million of the 3 million population of Mongolia, encompassing many migrants from the provinces.
- Inclusion of a wide sampling of clinical conditions.
- Generalisability of findings to other regions of the country and other conditions likely given the apparent universal use of the patient-held health Booklets for all citizens, and the high literacy rate across the country.
- Applicability of findings to other countries of the Central Asia region likely since Mongolia and its health system share similarities with other former Soviet countries in Central Asia.

### Limitations:

- Although we surveyed patients about primary-care and private-care experiences, direct data from primary-care and hospital inpatient departments as well as private hospitals is necessary for a thorough assessment of the entire system.

## INTRODUCTION

A universal system of records, accessible by both patients and their attending healthcare professionals (HCP), is the holy grail of continuity of care. This is because information sharing facilitates the safe and effective handover of clinical care between care providers (termed clinical handover).<sup>1-6</sup> Information sharing with patients also facilitates patient-centred care and self-care by patients, thereby improving clinical outcomes.<sup>7-9</sup> The need for a clinical information system accessible to patients and providers has become greater as the proportion of patients with chronic diseases needing on-going care increases. While over half of deaths in Asia are attributed to non-communicable diseases (NCD)s, during this decade alone the global burden of NCDs will have increased by 17%, with the World Health Organization (WHO) estimating that by 2020, NCDs will account for 80% of the global burden of disease, causing 7 out of 10 deaths in low- and middle-income countries (LMIC)s.<sup>10 11</sup> NCDs disproportionately affect LMICs, where nearly three quarters of NCD deaths occur.<sup>11</sup> In most LMICs, patients carry pieces of paper and notes from previous HCPs as they shop around for on-going healthcare between public and private providers.

In this paper, we report a unique nationwide system of generic patient-held records (PHR) in Mongolia and its use for managing NCDs in outpatients.<sup>12</sup> Such systems have been successfully implemented in both high and low income countries for maternal and child health.<sup>13</sup> However, to our knowledge, Mongolia is the only country to institute a single, universally accessible, PHR system covering all conditions and groups of patients. Mongolia is a LMIC within Central Asia and a former Soviet Union (FSU) satellite state. Central Asia is a vast region and includes sixteen countries with a regional population of approximately 320

million.<sup>10</sup> Like other countries in the region and most LMICs, Mongolia is experiencing a demographic shift towards older populations.<sup>14</sup> Chronic NCDs (the leading cause of death in adults) are estimated to be responsible for 80% of all deaths in Mongolia and cause over 3.2 million deaths per year in this region.<sup>10</sup> The health systems in Mongolia and most of the FSU are in transition from a Soviet Semashko system to a primary-secondary care model providing a need and an opportunity to improve integration between primary and secondary care.<sup>15</sup> The most fundamental component of such integration is an effective information transfer during referral from primary care to hospitals, and during discharge or outpatients care from hospitals to primary care. Therefore, lessons from Mongolia's low-cost functioning universal PHR system may be relevant to the rest of the region and other LMICs.

Here we aim to: (a) describe Mongolia's universal Patient-held Health Booklets (hereafter referred to as the Booklet). (b) Describe the use of these Booklets and evaluate the adequacy of the information provided therein in the for patients with chronic NCDs in outpatients presenting to public hospitals in Ulaanbaatar, Mongolia. (c) Investigate possible differences in the provision of minimum essential data based upon patient vulnerabilities. (d) Explore HCP training and guidelines that promote optional information exchange via the booklets or other patient documents. The scope of this study was limited to the public sector as this is where the majority of the population seek care, including the most vulnerable who cannot afford private healthcare. In addition, the public sector is where improvements are most likely to be effectual across levels of care. This is due to the central coordination of public primary and secondary healthcare facilities at the Ministry of Health and Family Welfare (MOH). Lastly, we concentrated on NCDs because on-going transfer of information is essential for effective care in chronic disease patients who need repeated and continuing care from multiple providers requiring information on disease history and previous management.<sup>2 16 17</sup> Patient-held records



also have a significance for chronic disease patients as they need clear direction on optimal self-care activities.

## METHODOLOGY

### Design

Between January and March 2016, we studied a sample of chronic diseases patients attending the outpatient departments of public hospitals in Mongolia and analysed the content of the written documents relating to their clinical care. We also investigated official policy and the training documents and guidelines relevant to information transfer and record keeping in Mongolia. Patients were not involved in the design of this study, but the findings will be disseminated through the Mongolian partner non-for-profit organisation (Wellspring) to patient groups in Mongolia.

### Setting

Purposive sampling was used to select two large district hospitals from the 12 public hospitals in Ulaanbaatar. The survey took place in the outpatient medical clinics (OPD) of these two secondary-care hospitals. All OPD clinics were conducted by doctors.

Information was recorded by doctors in three places: a) A Patient-Held Health Booklet; b) A follow-up “AM11” booklet where they wrote similar notes and doctors stored them in the clinic; And c) an electronic system called HealthInfo which was accessible on computers within that hospital’s OPD but not elsewhere. (See online supplementary appendix 1 for a full description of our study hospitals and healthcare system in Mongolia.)<sup>14 15 18-21</sup>

### Population

*Inclusion criteria for surveyed patients* were a) age >17 years, and b) that they were waiting to seek doctor's advice for at least one of the following tracer conditions: diabetes, hypertension, cardiovascular or cerebrovascular disease, respiratory, gastrointestinal, or kidney disease.

*Exclusion criteria* were patients considered too unwell to participate with no carer informant and/or did not speak Mongolian or English language.

While researchers were at the clinics, all outpatients were invited to participate in the study and assessed for eligibility. All days and hours of clinic operation were randomly included for data collection.

### Interviews and patients' document review

Patients were interviewed both before and after their appointments. Patient recall was the only means of verification for the verbal information given to patients during doctor's clinic consultation. Any written handover information brought in (e.g. referral, test or prescription notes, and/or last provider notes in the Booklet) and taken out of the OPD doctor's room (e.g. reason for visit, management instructions, test or prescription notes in the Booklet) by the recruited patients was examined to collect the following information:

- 1) The type of document(s) used (the Booklet or other papers); and
- 2) The content of the written information according to a check-list.

### Data analysis

Data was entered in Microsoft Excel version 14.7.3 (Microsoft Corp, 2011) and analysed using SPSS version 22.0 (IBM Corp, 2013). Inferential statistics of bivariate and univariate logistic regression were used to identify associations between the patients' background characteristics and the quality of handover they experienced during this OPD visit. Three types of key information, identified as essential pieces of documented information that NCD patients should

be provided with, were selected to represent minimum information to be entered in the patient's document upon leaving the outpatients for a minimum handover quality: (i) diagnosis, (ii) prescription/management, and (iii) follow-up.<sup>22</sup>

For the effect of vulnerability upon written information provision on leaving the clinic, nine predictor variables, identified via stepwise regression and guided by previous research, describing vulnerable groups in FSU and LMICs, were selected for inclusion.<sup>23 24</sup> These were: hospital site; age; gender; ethnicity; highest level of education; socio-economic status; distance of residence from OPD; co-morbidities; and advice for what level of health service to visit next (a proxy for severity). For all regression analyses, two-tailed p-values were utilised, reflecting the non-directional nature of the alternative hypotheses, with a chosen significance ( $\alpha$ ) level of  $p \leq 0.05$ .

### Sample size

To estimate the proportion of doctors entering the three defined type of key information items within the handover documents upon leaving the outpatients, a minimum sample size of 385 was calculated based on a formula for accurately estimating proportions in an unknown population with  $\pm 5\%$  accuracy at the 95% confidence level ( $\alpha=0.05$ ).<sup>25</sup> There were no previous data to be used for sample size calculation from Mongolia, FSU, or LMICs.

### Policy, guidelines and training related to clinical information transfer for NCDs

Publicly available documents regarding legislation, policies and guidelines for clinical handover, the Booklets and related HCP training were sought in English and Mongolian. Snowball methodology<sup>26</sup> was used for identifying experts and informants through existing contacts.

Informants were consulted in our two hospitals, the Mongolian National University of Medical

Sciences, the World Health Organisation (WHO) Mongolia Office, MOH, and from an independent international senior health systems consultant working with MOH and the World Bank for two decades. These experts and informants were also asked regarding their awareness or experience of formal training offered to HCPs on how to use the booklets or other handover documents.

## RESULTS

### Demographic and health information

A total of 395 patients were recruited between 14th February and 10<sup>th</sup> March 2016 and were included in the analysis: 412 patients waiting to visit the doctors who met the inclusion criteria were approached, 12 refused to participate, and 5 were excluded due to not speaking English/Mongolian. Patient characteristics and their main clinical conditions are described in Table 1.

Table 1 - Patient background and health information

<b>Demographic and health information</b>	<b>Males (n=158) No. (%)</b>	<b>Females (n=237) No. (%)</b>	<b>Total (n=395) No. (%)</b>
<b>Hospital site</b>			
<i>Site A</i>	91 (57.6)	122 (51.5)	213 (53.9)
<i>Site B</i>	67 (42.4)	115 (48.5)	182 (46.1)
<b>Age</b>			
<i>Years (mean <math>\pm</math> SD)</i>	54.2 $\pm$ 12.8	50.9 $\pm$ 15.5	52.2 $\pm$ 14.6
<b>Ethnicity</b>			
<i>Khalkh</i>	141 (89.2)	221 (93.2)	362 (91.6)
<i>Other</i>	17 (10.8)	16 (6.8)	33 (8.4)
<b>Highest level of education</b>			
<i>Incomplete vocational/secondary</i>	18 (11.4)	25 (10.5)	43 (10.9)
<i>Complete vocational/secondary</i>	92 (58.2)	122 (51.5)	214 (54.2)
<i>Complete graduate</i>	48 (30.4)	90 (38.0)	138 (34.9)
<b>Employment status</b>			
<i>Unemployed</i>	81 (51.3)	84 (35.4)	165 (41.8)
<i>Retired</i>	49 (31.0)	92 (38.8)	141 (35.7)
<i>Employed</i>	28 (17.7)	61 (25.7)	89 (22.5)
<b>Type of residence</b>			
<i>House</i>	59 (37.3)	85 (35.9)	144 (36.5)
<i>Apartment</i>	59 (37.3)	106 (44.7)	165 (41.8)
<i>Ger</i>	38 (24.1)	46 (19.4)	84 (21.3)
<i>Homeless</i>	2 (1.3)	0 (0)	2 (0.5)
<b>Number of other adults living in the same household</b>			
<i>0</i>	7 (4.4)	8 (3.4)	15 (3.8)
<i>1</i>	49 (31.0)	66 (27.8)	115 (29.1)
<i>2</i>	43 (27.2)	93 (39.2)	136 (34.4)
<i>3</i>	36 (22.8)	47 (19.8)	83 (21.0)
<i>4+</i>	23 (14.6)	23 (9.7)	46 (11.6)
<b>Number of children living in the same household</b>			
<i>0</i>	88 (55.7)	132 (55.7)	220 (55.7)
<i>1</i>	28 (17.7)	44 (18.6)	72 (18.2)
<i>2</i>	29 (18.4)	44 (18.6)	73 (18.5)
<i>3</i>	12 (7.6)	14 (5.9)	26 (6.6)
<i>4+</i>	1 (0.6)	3 (1.3)	4 (1.0)
<b>Socio-economic status</b>			
<i>Lower</i>	10 (6.3)	18 (7.6)	28 (7.1)
<i>Middle</i>	106 (67.1)	121 (51.5)	227 (57.5)
<i>Upper</i>	42 (26.6)	98 (41.4)	140 (35.4)
<b>Distance of residence from hospital</b>			
<i>Less than 1 hour</i>	127 (80.4)	203 (85.7)	330 (83.5)
<i>More than 1 hour</i>	31 (19.6)	34 (14.3)	65 (16.5)
<b>Health conditions</b>			

<i>Cardiovascular disease (excluding hypertension)</i>	85 (53.8)	138 (58.2)	223 (56.5)
<i>Diabetes</i>	72 (45.6)	92 (38.8)	164 (41.5)
<i>Hypertension</i>	29 (18.4)	46 (19.4)	75 (19.0)
<i>Cerebrovascular disease</i>	19 (12.0)	20 (8.4)	39 (9.9)
<i>Chronic gastrointestinal disease</i>	8 (5.1)	17 (7.2)	25 (6.3)
<i>Chronic respiratory disease</i>	3 (1.9)	19 (8.0)	22 (5.6)
<b>Morbidity status</b>			
<i>Single morbidity</i>	106 (66.5)	153 (64.6)	258 (65.3)
<i>Comorbidity</i>	53 (33.5)	84 (35.4)	137 (34.7)
<b>Referral from</b>			
<i>Self-referral</i>	30 (19.0)	26 (11.0)	56 (14.2)
<i>Primary-care</i>	101 (63.9)	165 (69.6)	266 (67.3)
<i>Secondary-care</i>	27 (17.1)	46 (19.4)	73 (18.5)

\* The variable “socio-economic status” was created using information regarding the type of accommodation and the number of adults and children living in the same household. This was generated in accordance with methods used by Mongolia’s National Statistical Office to define urban populations and grouped patients into three ordinal categories: lower, middle, or higher socio-economic status.[25]

### Patient-held health booklets: Government's Patient-Held Health Booklets

Figure 1 shows sample pages of a typical Government's AM20 Patient-Held Health Booklet.

The Booklet is meant to be carried by all patients in Mongolia. It is issued by the primary care family doctor or a hospital. If it runs out of pages and/or the patient could not obtain a new one in a timely manner from a health centre, he/she could purchase an unofficial alternative booklet in the market. The family doctor or hospital issued booklets or the unofficial booklets have the same size and function. They are A5 size and have basic demographic information documented on the cover-page and history or clinical handover information recorded on subsequent pages. Information from MOH, health systems experts and hospital managers revealed that the system of recording patient-specific handover information for primary care and secondary care outpatients in these Booklets has been in place for over ten years and was adopted due to a lack of consistently retrievable medical notes in both primary and secondary-care. An MOH Order endorsed and formalised the system in 2009 after its spontaneous adoption by healthcare providers and patients.<sup>12</sup>

Figure 1:

### **Documents on arrival and departure from OPD**

Before visiting the OPD, 266 (67.3%) had visited their State-provided primary care doctors or nurses and been referred to the hospital clinic; and 55 (14%) self-referred. The majority of the rest, 63(16%), had been referred by other hospital outpatient clinics (Table 1).

Upon arrival at the OPD, 379 (96.0%) patients brought written handover documentation with them from their previous healthcare provider: nearly all (373; 94%) had the Booklet. Most patients brought only one document (the Booklet, n=287; 71%), and 5 (1.8%) brought only one



other paper). The majority of the rest brought two documents (83; 21.0%): the Booklet and a prescription or test result.

A total of 16 (4.0%) did not have any documents with them upon arrival at the OPD clinic and they did not receive any written information on leaving the clinic either. Apart from these, during the OPD clinic visit, 380 (96.2%) patients were provided with written handover information from the doctor; most (367; 92.9%) of this took the form of notes in the Booklet. In most cases, the information in the Booklet was the only written document given to the patient (258; 65.3%). For some (112; 28.4%) in addition to the Booklet other paper documents were also provided. These documents varied in size and format, were purposive in nature (conveying specific information such as prescriptions or test results), and typically were loose, but occasionally were stuck inside of the Booklets (Figure 1).

#### Content of the Booklets and documents on leaving OPD clinic (Table 2)

As expected, the Booklets were the most comprehensive source of written handover information from previous doctor visits brought by patients on arrival, and from OPD doctors upon leaving the clinic. The completeness of the information in the Booklets was helped by the fact that all Booklets contained basic patient ID and demographic details on the front-page (Figure 1), and a continuous series of records enabled identification of co-morbidities and major past-medical history details. However, the rate of important content categories noted for the OPD visit by doctors was inadequate given the needs of chronic patients, e.g. upon leaving the clinic, only 61% had notes related to medication required after the clinic visit, and only 40% contained information about follow-up after the clinic visit. (Table 2)

Table 2 – Content of different handover documents provided by outpatient department doctor for the OPD visit during the survey

<b>Document contents</b>	<b>Booklet* (n=367)</b>	<b>Other** (n=152)</b>
<i>Date on notes</i>	295 (80.4)	96 (63.2)
<i>Healthcare provider identifiers</i>	59 (16.1)	39 (25.7)
<i>Patient identifiers</i>	367 (100)	99 (65.1)
<i>Presenting complaint</i>	148 (40.3)	9 (5.9)
<i>Test results if test performed prior to this visit (n=129)</i>	47 (36.4)	56 (3.3)
<i>Diagnosis for this visit</i>	252 (68.7)	45 (29.6)
<i>Prescription</i>	225 (61.3)	33 (21.7)
<i>Medication and/or long-term care advice</i>	185 (50.4)	32 (21.1)
<i>Lifestyle advice</i>	100 (27.2)	2 (1.3)
<i>Follow-up or review advice</i>	146 (39.8)	13 (8.6)

\* *Official government health booklet and unofficial health booklets*

\*\* *These were varied and included: test referrals, test results, prescriptions, referral forms, letters, cards, notes and scraps of paper with any relevant information written on them.*

The following relationships were found to be statistically significant in adjusted multivariate logistic regression analyses (Table 3):

- living >1 hour away from the OPD and attending site A decreased the likelihood of receiving written prescription/management information;
- living >1 hour away from the OPD, having comorbidity, and returning for follow-up to the same hospital as their last visit to a HCP, all independently decreased the likelihood of receiving written follow-up information; and
- attending site B increased the likelihood of receiving a written prescription/management information.

Table 3 - Results of adjusted logistic regression analyses examining associations between patient background characteristics and the likelihood of being provided with a written handover document containing prescription information, management information and follow-up information by the outpatient department doctor

Independent variables (predictors)	n= 395 (%)	Written handover document provided by OPD contains prescription information		Written handover document provided by OPD contains management information		Written handover document provided by OPD contains follow-up information	
		Adjusted		Adjusted		Adjusted	
		OR (95% CI)	P - value	OR (95% CI)	P value	OR (95% CI)	P value
Hospital site <sup>†</sup>							
Site A	211 (53.4)	1		1		1	
Site B	171 (43.3)	4.25 (2.65 – 6.81)	0.0001	2.65 (1.69 – 4.15)	0.0001	1.08 (0.69 – 1.69)	0.751
Age							
Years	382 (96.7)	0.99 (0.97 – 1.00)	0.062	0.99 (0.98 – 1.01)	0.231	1.01 (1.00 – 1.03)	0.192
Gender							
Male	154 (39.0)	1		1		1	
Female	228 (57.7)	1.32 (0.91 – 1.93)	0.146	1.17 (0.80 – 1.70)	0.422	1.09 (0.73 – 1.65)	0.666
Ethnicity							
Khalkh	350 (88.6)	1		1		1	
Other	32 (8.1)	0.54 (0.21 – 1.36)	0.190	0.54 (0.21 – 1.35)	0.185	0.63 (0.29 – 1.36)	0.238
Highest level of education							
Primary	41 (10.4)	1		1		1	
Vocational/secondary	208 (52.7)	1.04 (0.54 – 2.01)	0.903	1.62 (0.82 – 3.19)	0.167	0.78 (0.39 – 1.53)	0.463
Graduate	133 (33.7)	1.64 (0.77 – 3.51)	0.199	1.79 (0.82 – 3.89)	0.144	1.06 (0.48 – 2.34)	0.878
Socio-economic status							

<i>Lower</i>	28 (7.1)	1		1		1	
<i>Middle</i>	219 (55.4)	0.35 (0.16 – 0.79)	0.011	0.77 (0.34 – 1.73)	0.527	0.50 (0.23 – 1.10)	0.086
<i>Upper</i>	135 (34.2)	0.58 (0.24 – 1.39)	0.221	1.32 (0.54 – 3.19)	0.542	0.45 (0.18 – 1.08)	0.073
<b>Distance of residence from OPD</b>							
<i>&lt;1 Hour</i>	319 (80.8)	1		1		1	
<i>&gt;1 Hour</i>	63 (15.9)	0.92 (0.48 – 1.76)	0.802	0.28 (0.13 – 0.61)	0.001**	0.48 (0.27 – 0.87)	0.015
<b>Morbidity status</b>							
<i>Single morbidity</i>	247 (62.5)	1		1		1	
<i>Comorbidity</i>	135 (34.2)	1.27 (0.79 – 2.03)	0.326	0.91 (0.57 – 1.45)	0.681	0.55 (0.35 – 0.87)	0.010
<b>Advice for what level of healthcare provision to visit next</b>							
<i>Primary-care</i>	179 (45.3)	1		1		1	
<i>Secondary-care</i>	203 (51.4)	1.30 (0.82 – 2.05)	0.270	0.91 (0.58 – 1.41)	0.661	0.52 (0.33 – 0.80)	0.003

<sup>†</sup> The categories of the predictive variables that received ORs of 1.00 are reference categories

OPD Outpatient department

OR Odds ratio

CI Confidence intervals

### **Patients' use of the Booklets (Appendix Figure 1)**

The majority (316; 80.0%) of patients reported consulting their Booklets and associated “documents” at home. Nearly all patients (386; 97.7%) thought having written information after a visit to a doctor was important: 49% patients said that these were important for their own understanding and management of their condition, as well as communicating it to others, and 27.9% said it helped to get faster service when in healthcare centres.

It should be noted that the patients' responses were not prompted by the interviewer since options were not read out. Positive and negative viewpoints were specifically requested, and patients were able to provide more than one answer.

### **Verbal communication with patients during clinic visit**

Almost all patients (99.4%) reported receiving some form of verbal handover information from the OPD doctor regarding future healthcare follow-up visits (Figure 2) while only 3.2% (24) recalled being advised to make lifestyle changes.

Figure 2:

A comparison of the written and verbal handover information provided by OPD doctors revealed some discrepancies between what patient recalled and what was written in the notes.

### **Private healthcare providers' use of the Booklet**

A total of 106 (26.8%) patients had visited a private healthcare facility at some point before coming to the OPD. Of these individuals, 82 (77.4%) reported that the private doctor looked at the Booklet information brought by the patient during the consultation and 60 (56.7%) reported that the private doctor added written information in the Booklet.

Documentation on policies, guidelines or training related to the patient-held health booklets or other system of clinical and information transfer

Overall, 16 managers, policy makers, medical school academics and 12 clinicians were consulted. Although we selected NCD patients for this study, it was clear from policy makers, managers, clinicians and patients, that all people in Mongolia have the Booklets for their healthcare records. A Government (MOH) Order<sup>12</sup> was found re-enforcing the use of the Booklets. However, no other official verdicts or documents could be found related to these Booklets. No written guidelines or training material for the use of Booklets or other system of information transfer were known to the clinicians in our clinics or available at the Medical University, MOH or WHO level. Similarly, no formal training related to the use of the Booklets or clinical handover in general was reported.

## DISCUSSION

We have described a unique and simple universal system of patient-held health records in Mongolia. Our main findings are that Patient-Held Health Booklets are a well-accepted and well-utilised method of recording patient-specific information in Ulaanbaatar, Mongolia. All people in Mongolia have these Booklets for their healthcare records. Booklets were used by healthcare providers routinely, irrespective of other electronic or in-house systems of note keeping, and provided a patient-centred functional record of consultations. Our study confirms that patients with a range of long-term conditions valued the Booklets and referred to them. However, the fact that these Booklets were widely used did not mean that their use was optimal. Not all important information was entered and there were discrepancies in the provision of information across the two hospitals and for specific patient groups. These issues suggest the need for staff training, handover guidelines and monitoring, all of which were found lacking.

Strengths of the study include the reduction of recall bias by interviewing patients immediately before and after the clinic consultation. The sample was from Ulaanbaatar, which accommodates 1.1 million of the 3 million population of Mongolia and included wide sampling of clinical chronic NCDs. Given the apparent universal use of the Booklets for all citizens, and the high literacy rate across the country, our results are likely to be generalizable to other regions of the country and all conditions. Study limitations were that although we enquired about primary-care and private-care, primary data from primary-care and hospital inpatient departments as well as private hospitals would be necessary for a thorough assessment of the entire system.

No other publications have described a nationwide universal patient record system, and, to the best of our knowledge, none have investigated NCD outpatient systems for clinical handover

processes in LMICs. An argument against the use of such universal PHRs is that they are time consuming to complete. Particularly, if electronic systems exist, clinicians would be expected to show reluctance to enter the same data in both electronic and handwritten records. However, our data show that doctors were reasonably vigilant in documenting information in the Booklets, despite being required to enter the same information into the electronic health record system. The tradition of Maternity and Child records held by mothers in both high and low income countries further demonstrates that such systems can work efficiently and be well received by the patients and providers.<sup>13</sup>

There is evidence that clinical handover between care providers can be a critical fault line in safe and effective care.<sup>1-6</sup> The Mongolian experience, in a highly literate population, shows that it is feasible to introduce a single booklet for information transfer between providers and between providers and patients. Such a booklet may represent 'intermediate technology' filling the gap between totally inadequate and random modes of information transfer and a comprehensive universal electronic health record system. Verbal information given to patients is also important for a patient-centred-care and is a common of clinical handover in all countries. In our study, in majority of cases, OPD doctors engaged patients in the handover process by providing verbal information about their condition and its management during consultations. However, the provision of information (recalled by patients) remained inadequate as judged by minimal criteria. Whatever was communicated by the doctor, the global literature (mainly from HICs) confirms that even educated patients can struggle to absorb the verbal information offered by healthcare providers during consultations.<sup>27</sup> This poor recall makes the written information even more important for chronic disease patients who need to act on the advice, provide self-care in an on-going basis, and visit multiple providers.



The implications from this study extend beyond Mongolia. There is an urgent need to improve the management of NCDs in LMIC and particularly at primary care.<sup>22</sup> Without adequate information transfer between primary and secondary care providers and with patients, this priority cannot be achieved. Throughout Central Asia and many LMICs, patients carry their own referral letters, test results, and pieces of paper-notes from one HCP visit to the next as they shop around for providers.<sup>28</sup> The recent implementation of healthcare reforms in Mongolia and FSU countries<sup>15 18 21 29</sup> provides an opportunity for increasing integration of services through tangible improvements in information exchange and handover processes between primary and secondary-care to be made whilst the health system is still developing. Patient-Held-Booklets, like those in Mongolia, provide a basic organised record in place of what might otherwise be disparate collection of notes on separate pieces of paper. This more coherent set of notes enables providers to build management choices upon the patient's history. Such organised notes in a booklet also improve patient-centred-care and empowerment because patients can better follow what is happening with their own care. Ultimately, the introduction of such a booklet, with provider guidelines and training of providers, could potentially improve outcomes for the growing number of patients with chronic NCDs and increase efficiency in a LMIC health systems under pressure and a higher utilisation of primary care.<sup>22</sup> There is a critical need for research in clinical handover and patient-centred care as related to NCDs in LMICs in order to promote continuity and integration of care and improve patient outcomes.

For Mongolia itself, the use of the Booklets can be further enhanced, since they are currently not being completed adequately. Recommendations include the introduction of a few structure formats in the Booklet, standardisation and guidelines as well as training for clinicians on what essential information should be provided on each visit. Better completed Booklets may enable the reduction in one tier of notes, namely the handwritten ones for in-house records.

Implementation of such changes is relatively low-cost<sup>30</sup> and could improve clinical handover between levels of providers in Mongolia, thereby promoting patient-safety, service integration and patient-centred care.

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## STATEMENTS AND DECLARATIONS

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### Contributors

HI: substantial contributions to conception and study design, acquisition of data, analysis and interpretation of data, drafting the article, revising it critically, and final approval of the version to be published. UM: substantial contributions to study design, acquisition of data, analysis and interpretation of data, and final approval of the version to be published. CH: contributions to analysis and interpretation of data, revising it critically, and final approval of the version to be published. CO, AT, IN: substantial contributions to conception and design and contribution to the drafts of the manuscript. SM: conception of the study question, substantial contributions to study design, drafting the article, revising it critically, and final approval of the version to be published.

### Competing interests statement

None for all authors.

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### Data sharing

Data and tools are available upon request from the corresponding author.

### Ethics

The research was conducted in accordance with a protocol reviewed and approved by both the University of Birmingham's and the Mongolian National University of Medical Science's Research Ethics Committees. All patients gave informed consent before taking part.

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Figure 1: Pages from the patient-held health booklet

- a) Front page
- b) Inside of front page
- c) A page of clinical notes
- d) A page with test results stapled inside the Booklet

Figure 2: Frequency & Type of Verbal Recommendations Given For Future Healthcare by OPD Doctors

Appendix Figure 1: Frequency & Types of Opinion Given by Participants on the Importance of Handover Document Provision from OPD



## Online supplementary Appendix 1

Mongolia is an upper middle-income country with a population of approximately 3,057,778.<sup>19 20</sup> The country is a large territory but sparsely populated with a Siberian climate, deserts, steppes, and mountainous terrain, which makes healthcare provision difficult, especially for rural populations.<sup>19 20</sup> Since 1990s, the introduction of Family Medicine has been one of the most significant healthcare developments to take place in Mongolia and the other FSU countries of Eastern Europe and Central Asia.<sup>21 29</sup> Prior to the major socio-political changes of early 1990s, these countries had a Semashko health system that emphasised curative over preventative care. This resulted in the creation of large hospital networks with an underdeveloped primary-care sectors. The aim of Family Medicine was to mitigate this by training general practitioners and establishing them in the community within Family Group Practices (FGP).<sup>18 21 29</sup> Whilst implementation has been a relative success in Mongolia, there is now a need to improve the integration of primary and secondary healthcare services so as to ensure a more seamless service particularly for patients with chronic NCDs.<sup>21 31</sup>

In Mongolia, similar to most other FSU countries, the health system comprises primary-care (provided by FGPs), secondary-care (provided by district hospitals), and tertiary-care (provided by specialist hospitals). In Ulaanbaatar, there are 12 secondary care hospitals with inpatient and outpatients for general medicine, some of which are targeting particular professional groups such as the army, civil servants and railway workers. There is also an array of private hospitals, 7 of which have inpatients. A system of compulsory insurance is in place to ensure universal coverage and access to services.<sup>10 18 21</sup> Other important similarities between these countries include the huge economic and political changes that initiated the on-going period of

transition that now places them in the middle-income country profile and the peculiarly high rate of literacy, a legacy from the socialist period, which in Mongolia is 98.2%.<sup>15 20</sup>

As with most other FSU countries, Mongolia is currently experiencing a demographic shift towards older populations with higher rates of chronic NCDs.<sup>10 14</sup> This and the greater need for service integration indicates that optimal clinical handover practices are likely to have significant impact on patient outcome. Chronic NCDs represent the major cause of death and disability in Mongolia, particularly in younger age groups, and constitute 93% of the overall disease burden, with cardiovascular disease, diabetes mellitus, and cancer being the leading conditions.<sup>10 14 31</sup> The majority of sufferers are found in the capital city, Ulaanbaatar, where approximately half of the population resides.<sup>10</sup> The proportion of persons aged 60 years and above is set to double from 5.9% in 2010 to 12% in 2030 and likely to lead to a significant increase in the prevalence of chronic NCDs – which has already increased from 1.1 to 1.7 per 10,000 people between the years 2004 and 2015.<sup>10 14</sup>

In Mongolia, as with other FSU countries, some healthcare providers operate a basic electronic health record system. None, however, have achieved integrated or nationwide operation.<sup>15</sup> Uniquely, in Mongolia, there is a nationwide programme of unstructured patient-held health booklets that document written handover information at all secondary-care institutions.<sup>12</sup> This system has been functioning for over ten years, though it has not been formally described or assessed.

As there are no published data about clinical handover processes in FSU countries, we anticipated that in spite of cultural differences, a study conducted in Mongolia would be of

relevance to other Central Asian and possibly Eastern European countries with a former Semashko health system that have been undergoing recent reforms.