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DES DE MEDECINE GENERALE

par

Florian BESSEAU

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**L'INTERROGATOIRE INFORMATISE DU PATIENT
EN DEHORS DU TEMPS DE LA CONSULTATION EN SOINS PRIMAIRES :
UNE REVUE DE LA LITTERATURE A PARTIR DE MEDLINE.**

Président : Professeur Rémy SENAND

Directeur de thèse : Docteur Cédric RAT

Membres du Jury :
Docteur Jean-Pascal FOURNIER
Docteur Jean-Michel NGUYEN

*« La vie est courte, l'art est long, l'occasion fugitive,
l'expérience trompeuse, le jugement difficile. »
Hippocrate*

*« Cultiver les sciences et ne pas aimer les hommes,
c'est allumer un flambeau et fermer les yeux. »
Proverbe chinois*

*« L'autre est un autre-que-moi parce qu'il est relativement le même,
parce qu'il est à la fois semblable et différent. »
Vladimir Jankélévitch, 1960*

*« Aussi loin et différent que soit l'autre, l'autre est un autre moi-même. »
Christiane Taubira, 2013*

*« Elargir la perspective suppose d'œuvrer en commun avec les autres. »
Le XIV^e Dalai-Lama*

*« S'est-on déjà brûlé à la chaleur humaine ? »
Bensé*

*« Vivre simplement pour que simplement d'autres puissent vivre. »
Mahatma Gandhi.*

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Au moment d'être admis à exercer la médecine, je promets et je jure d'être fidèle aux lois de l'honneur et de la probité.

Mon premier souci sera de rétablir, de préserver ou de promouvoir la santé dans tous ses éléments, physiques et mentaux, individuels et sociaux.

Je respecterai toutes les personnes, leur autonomie et leur volonté, sans aucune discrimination selon leur état ou leurs convictions. J'interviendrai pour les protéger si elles sont affaiblies, vulnérables ou menacées dans leur intégrité ou leur dignité. Même sous la contrainte, je ne ferai pas usage de mes connaissances contre les lois de l'humanité.

J'informerai les patients des décisions envisagées, de leurs raisons et de leurs conséquences. Je ne tromperai jamais leur confiance et n'exploiterai pas le pouvoir hérité des circonstances pour forcer les consciences.

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TABLE DES MATIERES

L'ensemble du document qui suit a été rédigé en anglais, en cohérence avec l'ensemble des articles consultés dans le cadre de ce travail (les articles consultés étaient publiés en anglais), et en postulant que le travail réalisé pourrait lui-même aboutir le moment venu à une publication.

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ABSTRACT

Setting: To collect data about health and behaviours, providing patients with computerized tools could help clinicians, since they can access to this information in their electronic medical record. Computerized systems to collect interview data are implemented, though an actual benefit for the patient is unclear.

Objective: The study objective was to analyse the usefulness and impact of interview PGHD collection in primary care.

Methods: We performed a systematic review of Medline literature without date restriction.

Results: Among 2345 studies initially identified, 52 were finally analysed. None of the reviewed studies demonstrated a positive effect on morbidity or mortality, neither on patient quality of life. However, computerized PGHD collection was often more efficient than face-to-face data collection or at least as efficient as paper-and-pencil data collection, in various situations. Several authors highlighted that computerized tools might improve data collection. A positive impact was reported for the following health priorities: risky behaviours, detection of violence in the couple, elicitation of change based on risk assessment. A large majority of patients and clinicians reported that such tools were useful.

Keywords: Patient-generated health data (PGHD); Patient-reported outcomes (PRO); Clinical interview; Primary care; Systematic review.

Abbreviations

A-CASI: Audio Computer Assisted Self Interview
BMI: Body Mass Index
CAHPS: Consumer Assessment of Health Plans Study
CI: Confidence Interval
CVD: Cardio-Vascular Disease
EHR: Electronic Health Record
EMR: Electronic Medical record
GP: General Practitioner
MeSH: Medical Subject Headings
NA: Non-Available
NS: Non-Significant
OR: Odds Ratio
PDA: Personal Digital Assistant
PGHD: Patient Generated Health Data
PHR: Patient Health Record
PICO: Patient, Intervention, Comparison, Outcome
RR: Relative Risk
RTI: Research Triangle Institute
SD: Standard Deviation

INTRODUCTION

Identifying patient's main health concerns should be a priority for primary care providers (1,2). Passing by such information may lead to missing opportunities or inappropriate healthcare. However, collecting appropriate information (3) remains a challenge for clinicians, who face various obstacles to accurately collect then update the related data in electronic health records (EHR). Time constraints (4,5) along with many competing demands limit possibilities of time consuming activity, like a genogram interview which takes about 20 minutes (6,7).

Patients may often be able to provide relevant and updated data (8–16). Self-administered paper-and-pencil forms might be used to collect clinical data outside the encounter (e.g. in waiting room) rather than face-to-face. Digitalizing data is an obvious societal trend, facilitating data handling and management. Patient-facing computerized interview began with micro-computers arriving (17,18). The growing uptake of computer and the development of various internet-enabled devices such as smartphones and tablets brought new possibilities (19). A modality of data collection is widely used in surveys, using an audio component named “Audio Computer Assisted Self Interview” (A-CASI). Previous authors reported that this modality has a significant impact on social desirability distortion (20–24). Data collected using interviews must be distinguished from physical data captured by wearable sensor devices (that do not require patient participation) and present specific issues (25,26). Collecting data outside the visit must be distinguished from remote consultation.

In order to address time constraints for clinicians, a specific focus is relevant on processes that lie on the flow of clinical interview data, entered directly by patients using computerized tools outside the encounter, so that they are available for clinicians during the consultation. Piras described interweaving terminologies in this field (27,28). A white paper defined Patient Generated Health Data (PGHD) (29). Among PGHD, patient reported outcomes are data issued from patients' portals and patient health record (PHR). Putting computerized PGHD collection into daily practice is likely feasible (30) even if challenging issues remain at socio-cultural/ethical, technical and organisational/operational levels (29,31). Whether the benefits are worth it remains a priority question.

The usefulness and the impact of PGHD collection can be assessed by referring to various perspectives: 1) impact on patient-centered outcomes : morbidity, mortality, quality of life, or on patient perception of the usefulness of the process 2) impact of PGHD collection on physician-centred outcomes : provider perception of the usefulness of the process, or impact on health procedures 3) on quality of data made available to the physician at point-of-care.

We performed a review focusing on *computerized interview-like PGHD collection* to report the usefulness and impact of such PGHD collection in primary care practices.

METHOD

This review was conducted according to the key steps required for systematic reviews (32). Considering that evidence might be sparse, the literature review was based on a broad scope and was not restricted to randomized controlled trials.

Study identification and selection:

We conducted a systematic search of PubMed, not limited by dates of publication, on May 18, 2018. The request was elaborated by FB and CR with the help of a librarian (*Text Box 1*). Explanations are given in *Appendix 1*. We also searched the reference lists of selected studies, and we included studies identified during the initial search by hand. Abstracts and full texts were reviewed by one reviewer (FB) for inclusion. As PGHD is a recent terminology, we searched for related data collection process.

Text box 1 – PubMed request

(((((data collection[MH] OR medical history taking[MH]) AND (computer systems[MH] OR mobile applications[MH] OR patient participation[MH])) AND (general practice[MH] OR primary health care[MH])) OR ("patient generated health data"[MESH] OR "patient generated health data"[TIAB] OR "patient generated data"[TIAB] OR "PGHD"[TIAB]))

Inclusion and exclusion criteria:

The *inclusion* criteria for the studies included in this review were as follows: 1) collection of PGHD or assimilated; 2) data collection was based on computer or derived devices such as tablets and smartphones; 3) the collected data were those usually collected by clinical interviews during a medical visit (history, lifestyle, symptoms, patient preferences, etc.); 4) studies performed in a primary care setting; 5) studies written in French or English; and 6) the abstract was available. Considering that evidence might be sparse, inclusion criteria were not restricted to a PICO presentation (32).

The *exclusion* criteria were as follows: 1) no usefulness outcome assessment; 2) data collection not intended for clinical practice setting; 3) anonymous data-collection; 4) studies limited to messaging; 5) digitalization of paper-based questionnaires.

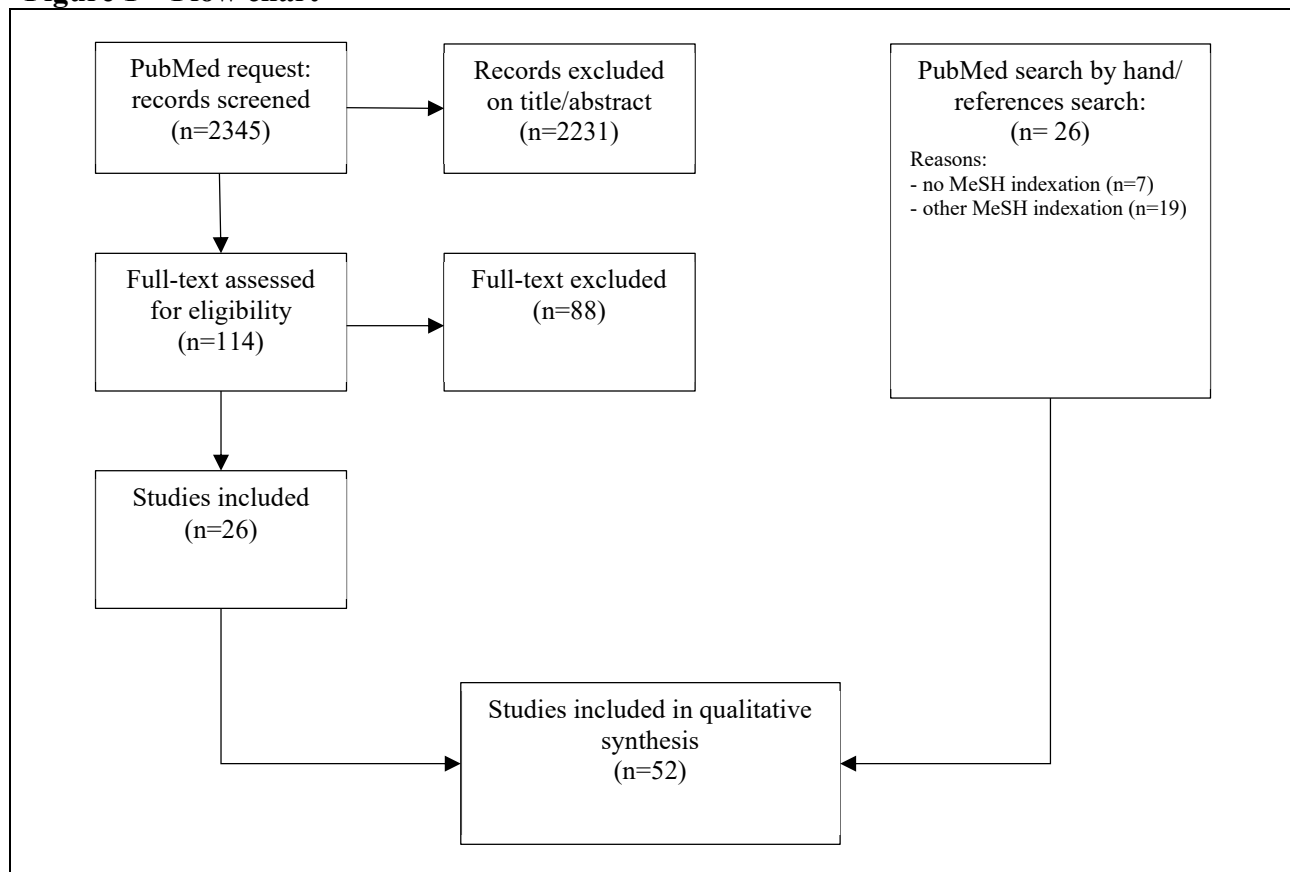
Data extraction and synthesis:

Studies were critically appraised by one reviewer (FB). The following data were extracted: participants (patients and clinicians) sample size and main characteristics, setting (countries, centres, practices), tool design and workflow, type of data collected by the tool, outcome measures assessing usefulness, study design and whether comparisons were performed. We performed narrative data synthesis, but no quantitative synthesis was performed because of the heterogeneity of the study designs and results presentation.

RESULTS

Among 2371 initially identified, 52 were finally analysed (Figure 1). Studies characteristics are described in Table 1. Forty were published between 2008 and 2018. They took place mainly in USA (n=38), or in Canada (n=4), UK (n=3), Australia (n=2), Netherlands (n=2), Germany (n=1), Korea (n=1), New Zealand (n=1).

Figure 1 – Flow chart



We first reported the impact of PGHD on patient-centered outcomes (Tables 2.A.a, 2.A.b, 2.A.c).

Impact of PGHD collection on morbidity outcomes and mortality (Table 2.A.a):

Four corresponding studies were found (33–36). None assessed mortality. Nagykaladi et al. (2013)(33) demonstrated that tailored recommendations based on the collection of 200 health risk factors might increase life expectancy (13 months vs 7 months, $p < .001$) after a 12 months follow-up of 200 patients allocated in 4 paired practices (intervention patients: mean age of 60.4 ± 11 ; female ratio of 72%; 95% high school educated; mean of 3.2 chronic conditions; smoking rate of 15%; mean BMI of 30.8 ± 6 ; mean of 4.95 visits per year).

Table 1 – Selected studies description:

Author, Year	Participants*	Age mean, min-max	Category of PGHD collection focused on	Modalities of data collection	Way of using the data
Acheson 2010 (37)	2330 patients 23 practices (3 centres)	50, 35-65	Familial history	Web-based	Categorized risk for cancer/ cardiovascular diseases Tailored recommendations
Ahmad 2009 (38)	140 patients (women) 1 clinic 11 physicians	43, >18 46	Intimate partner violence	Touch-screen program	Multi-risk assessment attached to medical chart Tailored recommendation/ contact sheet to patient
Ahmad 2017 (39)	75 patients (immigrants) 3 affiliated clinics 9 clinicians	36, 18-71	Mental health	Web portal accessed on touchscreen Completed in waiting-room	Printed reports with scored risk and tailored advice for patient/clinician
Arar 2011 (40)	35 patients (veterans) 1 centre	61, 29–88	Familial/personal history	Free broad-based online tool Linkable to a PHR portal	Online (editable)/printed
Arsoniadis 2015 (41)	50 patients 1 clinic	49, 18-74	Personal history Lifestyle Social items	Completed prior to the clinic appointment 2 alternatives: - online web patient portal - clinic-based tablet computers	Linked to EHR
Baer 2013 (42)	996 patients 5 practices	18-75	Lifestyle Familial history	Web-based Completed on a laptop just before the visit	Risk assessment EHR integration
Bajracharya 2016 (43)	200 patients 1 centre	55	Health care proxy	Web-based patient portal Prepopulated with data from EHR	EHR integration
Barr 2017 (44)	4421 patients 1 centre 15 clinicians	~50	Patient reported measure of shared decision making	4 alternatives: - online patient portal to EHR - tablet computers in clinic - interactive voice response - mobile phone text messages	EHR portal
Campbell 1997 (45)	354 women patients 2 practices 22 physicians	18-70	Pap smear history	A touch-screen program Completed in the waiting room	Printed reports for patient (local services)/for clinician
Chisolm 2008 (46)	929 patients 9 clinics 1 centre	11–20	Adolescent health 45-101 questions	Completed while waiting for visit on tablet	EHR integration
Chou 2010 (47)	30 patients 2 practices	41, 23-83	Personal history, medication Health maintenance Healthcare preferences	Web portal	Tailored recommendations to patients
Diamond 2010 (48)	24 patients	15	Youths health risk 54 core/39 follow-up items	Web-based Completed on computers in waiting rooms	Scored data EHR integration
Dove 1977 (49)	60 patients (women) 1 group practice (several doctors)	24	Medical history Social items 211 items	Completed on a terminal in a special room	
Ferrari 2016 (50)	74 patients (mainly immigrants) 3 sites (1 centre) 9 providers	37	Mental health Social items 52-items	Tablet-based Completed while waiting clinician	Report for patient/attached to the medical chart
Forjuoh 2014 (51)	83 patients 3 clinics (1 centre)	>18	Lifestyle Health beliefs/involvement	Intranet-based on a touch-screen device Completed in waiting room	Printed for patient/clinician
Fothergill 2013 (52)	90 parents of school aged children 4 practices 16 clinicians	33 7, 4-10	Childhood somatic concerns Parental depression 25 root questions	Web-based tool 2 alternatives: - computer in the exam room before visit - tablets in the waiting room	Paper copies/directly on tablet
Fuller 2010 (53)	68 practitioners multiple centres	49	Familial history	Computer-generated pedigrees considered overall	-
Geller 2008 (54)	142 patients 5 practices 18 providers	50-80	Colon cancer screening (risk factors, motivation)	Completed on an audio-enabled tablet before visit (not prepopulated) Adapted to elderly and low-literate people	Tailored education materials Printed reports
Goodyear-Smith 2013 (55)	196 patients 2 practices 7 physicians	>16	Lifestyle Mental health Exposure to abuse	Web-based Completed on a tablet in the waiting room	On the website/in the EHR
Grant 2008 (34)	244 patients 11 centres	56	Type 2 diabetes control and barriers to therapy	PHR with data retrieval from EHR	Tailored decision support Care plan printed/to EHR
Harrison 2003 (56)	692 patients (mainly female) 7 high schools (same school district)	16 (>12)	Lifestyle Psychosocial health 14 risk domains	Completed on a computer before visit	Printed scored results
Jones 2011 (57,58)	1068 patients (identified at risk) 2 clinics	63	Cardio-vascular risk factors	Web-based questionnaire Completed in the clinic on touchscreen Automatic EHR data retrieval	Stratified risk Impact of risk factors modification
Kason 1984 (59)	100 patients 1 centre	18-65	Lifestyle	Computer program Completed while waiting for clinician	
Klevens 2011 (60)	80 patients 1 women health clinic	35	Intimate partner violence	Audio-enabled touch screen software Completed in examination room before/after visit	Printout of local resources ± video encouraging help seeking
Mangunkusumo 2005 (61)	380 patients 24 classes from 5 secondary schools	14, 13-17	Adolescent health and healthcare utilization	Generic secure internet tool	Accessible to school physician/nurse
Murray 2013 (62)	663 patients 4 clinics	21-75	Familial history	3 alternatives: - online portal - laptop computer in waiting room - interactive voice response	-

Author, Year	Participants*	Age mean, min-max	Category of PGHD collection focused on	Modalities of data collection	Way of using the data
Nagykaldi 2012 (63)	279 adults	40-75	Personal history, medication	Web based with access to data from EHR	Tailored patient care plan Printed/electronically accessed through portal
	+116 parents of children	2-5	Health maintenance	2 alternatives: - over the internet	
	4 centres		Symptoms tracking Healthcare preferences	- portals kiosks at the office	
Nagykaldi 2013 (33)	200 patients 4 paired practices	60	Lifestyle/quality of life Familial/personal history Mental health 200 health risk factors	Web-based PHR accessible over the internet	Tailored recommendations Patient feedback of their impact on estimated life expectancy
Nundy 2014 (64)	Diabetic patients	NA	Diabetes self-care activity (knowledge/beliefs, skills, behaviours, adherence)	Automated mobile phone text messages	Alert to nurse-practitioner
	1 centre 12 physicians			Tailored health information/questions	Summary of data exchanged to patient/provider
Olson 2009 (65)	98 patients	11-19	Adolescents health Familial/personal history	Personal digital assistant (PDA) based tool	Tailored educational messages
	5 practices 13 physicians		Motivation to change 60 core questions	Completed immediately before visit	On the PDA/printed
Paperny 1990 (66)	294 patients 2 adolescents clinics	15, 13-19	Adolescents health 32 screening questions	Laptop program Advanced reliability checking capability	Personalized printout Counselling/local resources Coded number for clinician
Park 2018 (67)	3599 clinic patients/ 329 general users	NA	Lifestyle/quality of life Medication	PHR mobile application Access to data from EHR	Cardiovascular risk score EHR integration
	1 centre		Symptoms		
Phillips 2014 (68)	1707 patients 9 practices	49	Lifestyle, mental health 17 screening questions	Web-based 2 alternatives: - over the internet - in the office	Patient advice/goal setting Results printed/faxed to clinician
Poon 2007 (69)	179 patients 7 practices	NA	Prevention items	Web portal to a PHR Familial history data from another module Completed before visit	Patient option choice on way to handle due items
Probst 2008 (70)	31 patients with type 2 diabetes	61, 18-75	Dietary intake history	Web-based	Dietitian interface to elaborate individualized plan, sent to GP
	1 centre				
Radley 2006 (71)	204 patients (women) 2 practices, 3 clinics	53 (> 16y)	Pelvic floor related symptoms	Web-based Completed on a touchscreen prior to visit	-
Rogausch 2009 (72)	280 patients	62	Quality of life	Tablet computers Completed in the waiting room	EHR integration Printout with results of previous data collection
	27 assistants	33			
	17 GPs	50			
Rubinstein 2011 (73)	3283 patients 41 practices	50, 35-65	Familial history Lifestyle Screening tests uptake	2 alternatives: - online at the study website - at computer in the physician's office	Stratified risk Tailored prevention messages
Ruffin 2011 (35)	3344 patients 41 practices	50, 35-65	Familial history About 6 diseases	Online	Risk-tailored messages
Schnipper 2008 (74)	466 patients 4 practices	NA	Medication reconciliation Adherence/understanding	Patient portal Prefilled form with EHR data	EHR integration
	(same network)		Allergies/adverse effects	Completed before visit	
Skinner 1985 (75)	60 patients 1 practice 12 practitioners	36	Lifestyle	Computer terminal Completed before appointment	EHR integration
Slack 2012 (76)	26 patients 1 centre	21-72	Familial/personal history Social items	Portal with access to patient's EHR Completed by patients at home before first appointment	Responses available on doctor's computer screen
	6 clinicians		233 core questions, up to 6000		Patient: printed (contacts) Clinician: printed before visit/mailed 2-3 days later
Stevens 2008 (77)	878 patients 9 clinics (1 centre)	14, 11-20	Adolescent health 45-100 items	Internet-based application Completed in waiting-rooms on tablet	Parents encouraged to talk to the child's physician
Thompson 2007 (78)	1846 sessions by parents of children	All age children	Children health (12 modules)	Touchscreen kiosks in public places (fast-food, library, administrative office)	
Turvey 2012 (79)	18471 patients (veterans)	60-69	Medication list	Web-based patient portal containing a PHR	EHR linkage
van den Brekel-Dijkstra 2016 (36)	129 patients 4 integrated centres	45-70	Cardio-vascular risk factors Motivation 75 questions	Web-based Completed over the internet	Cardio-vascular risk Patient referral to local/online offers
Wald 1995 (80)	172 new patients	37, 17-88	Symptoms (systems review) Lifestyle	Completed in the clinic waiting room at a computer terminal	Printed for patient/provider
	28 physicians		Preventive items	Data retrieval from central clinical database	Recorded to central clinical database
Wald 2010 (81)	2027 patients 11 centres	49	Medication list/allergies Diabetes follow-up	Web portal to a PHR Completed before visit	Goal setting
	89 physicians	41	Personal/familial history	Prepopulated with EHR data to review	EHR integration
White 1984 (82)	100 patients	>16	Lifestyle Familial/personal history	Television monitor and a numeric keypad	Printed results
	1 practice		Prevention items Screening tests	Completed in the waiting room	
Wright 2011 (83)	396 patients 11 practices	47		PHR	Patient option choice on way to handle due items
	80 practitioners	41		Access to EHR data for review by patient	EHR integration
Wu 2013 (84), 2014 (85)	1184 patients	58, 18-92	Familial history About 48 diseases	Patients prepared data entry in advance Completed at a dedicated clinic kiosk prior to appointment	Risk stratification Clinical decision support Recommendations for patient/clinician
	2 clinics of 1 centre 14 providers	29-65			

Notice that sum of studies detailed in Table 1 is not equal to those in Tables 2 because some studies assessed multiples outcomes.

* Number of patients effectively exposed to the tool.

Grant et al. (2008)(34) assessed a tailored decision support tool in a randomised study that included 244 patients. Data collection was focused on type 2 diabetes control and barriers. Grant demonstrated a more frequent intensification of cardio-vascular treatment: 53% vs 15% ($p<.001$), but the study did not demonstrate any impact on morbidity outcomes. Ruffin et al. (2011)(35) performed a large cohort study that included 3344 patients from 41 practices, in order to assess the impact of tailored messages based on patient reported data (versus generic messages). The study demonstrated an increase of fruits/vegetables consumption (OR=1.29; 95% CI [1.05-1.58]) and physical activity (OR=1.47; 95% CI [1.08-1.98]) after a 6 months follow-up period, but there was no impact on smoking cessation. Van den Brekel-Dijkstra et al. (2016)(36) performed a survey in a random sample of 129 patients who were exposed to a cardio-vascular risk assessment tool with automated local referral. Forty (31%) reported having initiated health behaviour change after a 6 months follow-up period, either related to physical activity ($n=41$, 32%) or eating ($n=36$, 28%).

Table 2.A.a – Impact of PGHD collection on morbidity outcomes and mortality:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
		Cardiovascular treatment intensification	53% vs 15% ($p<.001$)	
Grant 2008	Experimental	Diabetes related risk factors (after 12 months follow-up period)	NS	Active control (randomized)
	Quasi-experimental (pre/post and here/elsewhere)	Estimated life expectancy increase (after 12 months follow up period)	13 months vs 7 months ($p<.001$)	Active control (not randomized)
		Patients reporting having:		
		- increased fruits and vegetables consumption from ≤ 5 to ≥ 5 servings/day	OR=1.29; 95% CI [1.05-1.58]	
		- increased physical activity to 5-6 times/week for ≥ 30 min/week	OR=1.47; 95% CI [1.08-1.98]	
Ruffin 2011	Comparative: risk-tailored/generic preventive messages	- quit smoking, increased aspirin use (after 6 months follow up period)	NS	No control (randomized)
		Patients reporting:		
		- health-behaviour change initiating	31% (40/129)	
		- increased physical activity	32% (41/129)	
		- healthier eating	28% (36/129)	
van den Brekel- Dijkstra 2016	Quasi-experimental (pre/post)	- reduced alcohol intake (after 6 months follow up period)	24% (23/96)	No control (random sample)

Impact of PGHD collection on quality of life (Table 2.A.b):

Some studies collected data related to patient quality of life (71,72,86) but only one, performed by Nagykalai et al. (2013)(33), assessed whether PGHD collection might modify patient perception of health. This specific study demonstrated an increase of *perceived health* after a 12 months follow-up period among patients who participated to a PGHD collection (OR=4.94; 95% CI [3.85–6.36]).

Table 2.A.b – Impact of PGHD collection on quality of life:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
	Quasi-experimental (pre/post and here/elsewhere)	Self-rated overall health [on a 0 to 4 scale] association with tool use (after a 12 months follow-up period)	OR=4.94; 95% CI [3.85–6.36]	Active control (not randomized)
Nagykalai 2013				

Patient perception of PGHD collection usefulness (Table 2.A.c):

Among 25 studies that reported this outcome, 19 provided a quantitative assessment, based on a Likert scale in 10 studies (38,46,47,50,52,69,71,74,75,81). In most studies, this assessment was performed either just after tool use or after a clinical visit. Only 5 studies included a control group. 80% (Kason et al., 1984 (59)) to 94% (Arar et al., 2011(40)) of patients reported that the tool allowing PGHD collection was *useful*. A large majority of patients who were interviewed reported that the tool they experimented *could help to support care*, rates varying from 60% to 94% (47,48,71,72,84). Patient rated tools as helpful with a mean of at least 8/10 (Slack et al., 2012 (76), Ferrari et al., 2016 (50)). In another study (Fothergill et al., 2013 (52)), a large majority of patients (89%) reported that the tool might especially *facilitate sharing their concerns with the physician*. These results focusing on usefulness are consistent with the findings of qualitative studies (Nagykaldi et al., 2013 (33), Chou et al., 2010 (47)). Other authors reported the proportion of patients who found these tools *appropriate* (47,52,55,71); rates varied from 93% (Goodyear-Smith et al., 2013 (55)) to 51/105 (Radley et al., 2006 (71)), with a mean of 4.3 ± 0.7 in another study (Ferrari et al., 2016 (50)). Despite an overall decrease in usage of the tool, Park et al. (2018)(67) identified a persistent use for some items (weight, blood pressure, 10-y CVD risk ...). Nagykaldi et al. (2013)(33) reported an increase in patient-centeredness of care with tool use: +0.81 on a 10-point scale ($p=.05$). Wald et al. (2010)(81) observed an increase in *concern discussion* or *preparedness* in accordance with the type of data collected. Chisolm et al. (2008)(46) reported 60% of adolescents highly *satisfied* with the tool, more likely to assess the tool as useful (OR=2.18; 95% CI [1.63-2.62]).

We then reported the impact of PGHD collection on physician-centred outcomes (Tables 2.B.a, 2.B.b).

Physician perception of PGHD collection usefulness (Table 2.B.a):

13 studies (7 qualitative) focused on the perception of physician toward PGHD collection. Main themes were facilitation of the visit notably about *communication* (especially for *sensitive issues*), and balancing breadth and depth of the content of the visit.

Data were sparse and inconsistent. About main quantitative assessment: Slack et al. (2012)(76) observed a mean of 7.7/10 for *help to patient* and 7.5/10 for *help to provider* to enhance cares. In the study of Wu et al. (2013)(84) a large majority of physicians reported a *practice improvement* (12/14), or *practice facilitation* (11/14), while in the study of Nundy et al. (2014)(64), only 3 clinicians on 12 reported a change in their practice. Wald et al. (2010)(81) observed that patient *preparedness* and frequency of *EHR update during the visit* were different depending on the category of data considered.

Table 2.A.c – Patient perception of PGHD collection usefulness:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
		Mean benefits of tool/quality of subsequent visit, assessed on the Computerized Lifestyle Assessment Scale [5=strongly agree]	3.8 [SD=0.67]	
Ahmad 2009	Experimental	Score difference by violence status Patients assessing tool useful	NS 94%	Control (randomized)
Arar 2011	Cross-sectional	Qualitative Patients highly satisfied	Benefits for relatives 60%	No control (random sample)
		2 items each rated on a 5-point Likert scale (enhancement of communication/of care): - mean among highly/less satisfied patients - association with highest satisfaction	4.35 / 3.66 OR=2.18; 95% CI [1.63–2.62]	
Chisolm 2008	Cross-sectional	Association between satisfaction and computer experience/screening result Patients agreeing that tool: - was a valuable resource - improved patient-provider interactions - facilitated participation in their own care - was helpful for informed decision making - was helpful to improve their health - will likely help to continue improve health	NS 83.3% (n=25) 60.0% (n=18) 80.0% (n=24) 73.3% (n=22) 60.0% (n=18) 70% (n=21)	No control (not randomized)
Chou 2010	Cross-sectional	Qualitative	Tool in general found helpful	No control (random sample)
Diamond 2010	Cross-sectional	Adolescents finding tool helpful during visit Patients' mean tool rating on a Likert scale: - About questions on psycho-social health: - tool was appropriate - tool will help providers questioning - Tool can improve providers' assessments - Tool would save provider's time	94% Overall: 4.1 [SD=0.7] 4.3 [SD=0.7] 4.0 [SD=0.8] 3.9 [SD=0.9] 4.1 [SD=0.9]	No control (not randomized)
Ferrari 2016	Cross-sectional	Patients agreeing that the tool: - was a good way to ask routine questions - helped with sharing of concerns Qualitative interview	92% 89% Increased visit efficiency, helped: to focus discussion, problem identification, in-depth exchanges, validated concerns	No control (not randomized)
Fothergill 2013	Cross-sectional	Patients finding the tool appropriate	93% (175/188)	No control (not randomized)
Goodyear-Smith 2013	Cross-sectional	Qualitative Patients considering that: - they learned something about their lifestyle - they were reminded of risk factors - the tool was useful for physicians (after the 2nd use, 10-21 days after the first)	Efficient, good use of wait time, helped: doctor, relationship, self-reflection 55% of men and 44% of women 80% of both men and women 79% of men and 80% of women	No control (not randomized)
Kason 1984	Quasi-experimental (pre/post)	Mean scores differences for: - pleasantness [4-item scale] - difficulty [4-item scale]	3.0 [SD=0.8] vs 2.7 [SD=0.9] (p≤.01) 3.9 [SD=0.6] vs 3.6 [SD=0.7] (p≤.01)	No control (not randomized)
Mangunkusumo 2005	Comparative: internet/paper-and-pencil	Preferred data collection modality (after 4 weeks follow-up period)	Portal in all group but phone	No control (randomized)
Murray 2013	Comparative: portal/laptop/phone voice script			Control (not randomized)
Nagykaldi 2012	Cross-sectional	Patients feeling the tool: - was a valuable resource - facilitated participation in their own care	83% 80%	No control (not randomized)
Nagykaldi 2013		Patient-centeredness of care measured by the CAHPS PCC-10 [10-point scale]: - pre-post score difference - association with tool use	Increase of 0.81 points: +0.28 vs -0.53 (p=.05) OR=1.21; 95% CI [1.12-1.30]	
	Quasi-experimental (pre/post and here/elsewhere)	Qualitative (after 12 months follow-up period)	Relevant, motivating, helpful	Active control (not randomized)
		Adolescents: - perceiving responses confidentiality - feeling to be listened to carefully - with remaining unanswered concerns - being overall very satisfied	83.7% vs 61.5% (p=.002) 87.8% vs 64.6% (p<.001) 2.0% vs 10.8% (p=.03) 87.8% vs 63.1% (p<.001)	Control (not randomized)
Olson 2009	Quasi-experimental			

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
		Clinic patients/general users: - using the PGHD functions continuously - using it for more than 4 years - number of PGHD records evolution	175/3812 (81.14% of patients) < 1% Decreasing patterns, except for: - weight (slope=-685, $r^2=.85$) - blood pressure (slope=-526, $r^2=.88$), - 10-y cardiov. risk (slope=-47.2, $r^2=.55$) - blood glucose, metabolic synd. risk (lower increase, data not available)	No control (not randomized)
Park 2018	Retrospective	Patients thinking their providers had more accurate information	51%	No control (not randomized)
Poon 2007	Cross-sectional	Patient feeling more prepared for the visit	48%	No control (not randomized)
		Patients agreeing that tool was: - helpful - relevant	62/105 51/105	No control (not randomized)
Radley 2006	Cross-sectional	Patients agreeing it supported their cares	69% (192/280); 95% CI [63–75]	No control (not randomized)
		Qualitative (most frequent categories): - Tool helped patient being understood - Tool helped focusing on communication	46% (130/280) 41% (114/280)	No control (not randomized)
Rogausch 2009	Cross-sectional	Patients feeling that the tool: - gave provider more accurate information - enabled them to more prepared for visit	53% (39% neutral) 56% (35% neutral)	No control (not randomized)
Schnipper 2008	Cross-sectional	Intention to use computer modality	Threefold increase ($p<.001$)	No control (not randomized)
	Comparative: computer/ face-to-face/ paper-and-pencil	16-item assessment (rated on 5-point scale): most interesting modality	Computer ($p<.05$)	No control (randomized)
Skinner 1985		Helpfulness for patient: mean score on a 10-point scale	8.3/10	No control (not randomized)
Slack 2012	Cross-sectional	Patients considering that: - responses were important to their care - answers would be valuable to provider - computerized interview preferable	96% 97% 65%	No control (not randomized)
Wald 1995	Cross-sectional	Patients feeling (overall): - more prepared for the visit - provider had more accurate information - improved communication with provider - more satisfied with the visit - improved quality of care at the visit	55.9% 58.0% 37.2% (53.4% neutral) 37.7% (52.1% neutral) 24.5% (64.1% neutral)	No control (not randomized)
	Comparative: modules about: 1/ medication, allergies, diabetes 2/ health maintenance, family/personal history	After adjusting more arm 1 than arm 2: - discussed concerns with their provider - felt prepared for their visit	59.3% vs 46.3% ($p<.01$) 59.4% vs 50.9% ($p<.02$)	Active control (randomized)
Wald 2010		Patients finding: - the tool helpful - the pedigree helpful to them/their doctor - the tool raised their awareness of their disease risk/their familial risk - the tool changed their health conception (after 3 months follow-up period)	89.6% (n=403) 91.6% (n=415) / 91.7% (n=398) 85.1% (n=389) / 89.4% (n=415) 85.8% (n=393)	No control (not randomized)
Wu 2013	Cross-sectional			No control (not randomized)

Table 2.B.a – Physician perception of PGHD collection usefulness:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
Diamond 2010	Cross-sectional	Qualitative	Facilitated the visit, residents valued breadth of information	No control (not randomized)
			“Therapeutic effect”, tool ability to set a “mood of introspection”, easier identification of patients in need for help	No control (not randomized)
Dove 1977	Cross-sectional	Qualitative	Non-intrusive prompt to discuss mental health, no stigmatization, easier health assessment, facilitated the care planning	No control (not randomized)
Ferrari 2016	Cross-sectional	Qualitative	Increased visit efficiency, enabled being as focused as comprehensive, promoted in-depth exchange, no stigma about sensitive issues	No control (not randomized)
Fothergill 2013	Cross-sectional	Qualitative		No control (not randomized)
		Clinician thinking (whatever experienced): - a patient-generated computerized family history would contain more information than provider-generated - a patient-generated computer pedigree would improve their ability to assess risk	80% 73%	No control (not randomized)
Fuller 2010	Cross-sectional			No control (not randomized)

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
Goodyear-Smith 2013	Cross-sectional	Qualitative	Efficient to find out/address patients' needs, could contribute to enhance relationship, facilitated patients' engagement, no consensus about saving time	No control (not randomized)
		Providers feeling that the tool changed the care they provided	3/12	
Nundy 2014	Cross-sectional	Qualitative	Improved agenda setting, assessment of self-care, identification of patient barriers	No control (not randomized)
Rogausch 2009	Cross-sectional	Qualitative	GP valued facilitation of communication (notably about sensitive topics) and follow-up; Practice assistants valued patient-centeredness	No control (not randomized)
Slack 2012	Cross-sectional	Subsequent visit assessed on a 10-point scale [10="very helpful"] with 2 items: - Helpful for patient - Helped to provide better care	7.7/10 7.5/10	No control (not randomized)
		Questions perceived as most added-value	About psychiatric (100%), alternative care (93%), and medical review of systems (80%)	
Wald 1995	Cross-sectional	Providers assessing the tool facilitated discussion of sensitive topics	1/3	No control (not randomized)
Wald 2010	Comparative: 1/ medications, allergies, diabetes 2/ health maint., fam./pers. history	Arm 1 vs arm 2 providers: - finding that the tool helpful to patients - finding that the tool prepared patients before the visit - reporting to update EHR during visit	NS 100% vs 43% (p<.04) 89% vs 45% (p<.03)	Active control (randomized)
		White 1984	Qualitative "Doctors found the tool useful"	
Wu 2013	Cross-sectional	Providers thinking that: - the tool improved: - their practice - their understanding of family history - the tool made practice easier - proposed action plan was helpful - tabular pedigree was helpful	12/14 9/14 11/14 13/14 11/14	No control (not randomized)
		(After 3 months follow-up period)		

Impact of PGHD collection on medical procedures (Table 2.B.b):

20 studies analysed outcomes in this category. Various preventive procedures might be improved among participants who benefited from a PGHD collection, compared to usual care: Nagykaladi (2012, 2013)(33,63) reported a better uptake of various *recommended procedures* (84.4% vs 67.6% (p<.0001)), and a better use of various preventive services (OR=1.22; 95% CI [1.12–1.32]). Other authors reported an effect on *specific procedures*: completion of breast cancer screening based on mammography (48.6% vs 29.5% (p=.006), Wright et al. (2011)(83)), influenza vaccination uptake (22.0% vs 14.0% (p=.018), Wright et al. (2011)(83)), children immunizations (95.5% vs 87.2% (p=.044), Nagykaladi et al. (2012)(63)). However, Wright et al. (2011)(83) did not demonstrate any impact on other screening procedures.

Stevens et al. (2008)(77) reported that PGHD collection allows a better *identification of new concern* during visit (OR=2.94; 95% CI [1.81-4.76] (p<.001)). Ahmad et al. (2009, 2017)(38,39) reported that the following concerns were more discussed during the medical visit: mental health concerns (OR=2.2 (p=.02) (39), RR= 1.5; 95% CI [1.1 to 2.0] (38)), intimate partner violence (RR=1.4; 95% CI [1.1-1.9] (38)). On the contrary, Klevens et al. (2011)(60) did not found any difference when focusing on intimate partner violence.

Olson et al. (2009)(65) demonstrated that *remaining unanswered concerns* after visit were less frequent in adolescents who participated to a PGHD collection (2.0% vs 10.8% (p=.03)).

PGHD collection might allow more frequent *discussions on risks*. Phillips et al. (2014)(68) found that 34% of patients wanted to discuss risk (with an average of 0.8 ± 1.46 risks they wished to discuss). Geller et al. (2008)(54) found higher discussion rate about colorectal cancer screening (54.2% vs 29.6% (p=.04)) or colonoscopy (51.2% vs 25.3% (p=.04)). Olson et al. (2009)(65) found that fruits and vegetables intakes were more discussed during visit thanks to the tool (60.4% vs 41.7% (p=.03)); this discussion in particular was helpful for adolescents (58.2% vs 32.0% (p=.03)). But other authors did not find any significant difference (Baer et al. (2013)(42) and Murray et al. (2013)(62)).

Change intention was more frequent in Geller et al. (2008)(54) study (screening intention: 91.8% vs 43.4% (p=.01), NS for colonoscopy); Phillips et al. (2014)(68) and Jones et al. (2011)(57) found high percentage of people ready to change. Acheson et al. (2010)(37) demonstrated that calculated familial risk, based on patient-provided familial history, was often underestimated by patients. Nagykaladi et al. (2012)(63) found a slight increase in patient's activation on a 13-point scale (47 vs 45 points (p=.0014)).

Barr et al. (2017)(44) used a specific score to assess shared decision-making: digitalizing assessment had a negative impact on the score result (for online modality: OR=0.60, 95% CI [0.45-0.80]).

Table 2.B.b – Effect of the tool on medical procedures:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
		Association of calculated familial risk with patients' perception of: - risk to get disease - worry about getting disease - control over getting disease	strong association (p <.001) strong association (p ≤.01) no association	No control (not randomized)
Acheson 2010	Descriptive	Patient at moderate/strong risk perceiving themselves at average/below average risk	48–79%	
		Women intimate partner violence/control: - Discussion opportunity: risk raised by clinician/patient, based on audio record - Detection: present/recent risk identified, based on patient statement after visit	RR=1.4; 95% CI [1.1-1.9] RR= 2.0; 95% CI [0.9-4.1]	Control (randomized)
		Mental health: - Discussion opportunity - Detection	RR= 1.5; 95% CI [1.1 to 2.0] RR= 1.5; 95% CI [1.0 to 2.2]	
Ahmad 2009	Experimental	Substance abuse/sexually transmitted infect.	NS	
		Mental health symptoms: - patient-reported discussion - clinician detection (chart review)	58.7% vs 40.3% (p≤.05); OR=2.2 (p=.02) NS	Control (randomized)
Ahmad 2017	Experimental	Clinician screening reminders in EHR for moderate/high risk of colon/breast cancer	NS	Control (not randomized)
	Quasi-experimental (pre/post and here/elsewhere)	Patient-reported discussion during visit of family history/lifestyle factors/screening	NS	
Baer 2013	Comparative: online portal/ phone voice script/ phone text message/ paper/tablet	Patient-assessed shared decision-making scores [3-item scale] modality effect (compared to paper mode)/response rate	- online: OR=0.60, 95% CI [0.45-0.80]/34% - voice script: OR=0.45 [0.34-0.59]/25% - text message: OR=0.51 [0.38-0.67]/23% - paper: 12%, tablet: 41%	No control (not randomized)
Barr 2017				

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
		Women having updated pap-test, initially under-screened based on self-report	50-70 y: 46 (10/22) vs 14% (3/21) (p=.026) other women: NS	Active control (randomized)
Campbell 1997	Experimental	(after 6 months follow-up period)		
		Patient-reported:		No control (not randomized)
		- discussion about the tool report	30% (25/83)	
Forjuoh 2014	Cross-sectional	- collaborative goal setting about change	29% (24/83)	
		About colorectal cancer screening in general, and colonoscopy (CS) specifically:		No control (not randomized)
		- screening/CS discussed by provider	54.2 vs 29.6% (p=.04)/51.2 vs 25.3% (p=.04)	
Geller 2008	Quasi-experimental (pre/post)	- screening/CS recommended by prov.	49.2 vs 23.0% (p=.02)/43.4 vs 18.1% (p=.01)	
		- if due: patient intention to get screened/CS	91.8 vs 43.4% (p=.01)/NS	
Jones 2011	Cross-sectional	Patients choosing a change, to address a risk factor and reduce their calculated risk	Blood pressure: 91.4%, cholesterol: 93.3%, BMI: 90.5%, smoking: 57.1%	No control (not randomized)
		Women intimate partner violence:		Control (randomized)
		- disclosure rates difference	NS	
Klevens 2011	Experimental	- referral resources use rates difference	NS	
		Patients reporting having discussed family history with provider	NS	Control (not randomized)
Murray 2013	Comparative: portal/laptop/ phone voice script			
		Patients:		Control (randomized)
		- up to date for all recommended items	84.4% vs 67.6% (p<.0001)	
		- taking low-dose aspirin, if indicated	78.6% vs 52.3% (p<.0001)	
		- receiving anti-pneumoc. vaccination because of chronic health condition/age	82.5% vs 53.9% (p<.0001)/ 86.3% vs 44.6% (p<.0001)	
		Children up to date for immunizations	95.5% vs 87.2% (p=.044)	
		Patients' activation [13-item scale]	47 vs 45 points (p=.0014)	
		Patient-centeredness [10-item scale]	+0.32 vs -0.43 points (p=.037)	
Nagykaldi 2012	Experimental	(After 12-month follow-up period)		
		Overall rate of 10 preventive services	Intervention: 59.1% vs 63.3% (p=.001)/ control: NS	Active control (not randomized)
Nagykaldi 2013	Quasi-experimental (pre/post and here/elsewhere)	Up-to-dateness association with tool use (after 12 months follow-up period)	OR=1.22; 95% CI [1.12-1.32]	
		Proportion of visits including:		Control (not randomized)
		- discussions of risk	fruit/veget. intake: 60.4% vs 41.7% (p=.03), alcohol use: 53.9% vs 38.0% (p=.05)	
		- discussions of risk reported as helpful	fruit/veget. intake: 58.2% vs 32.0% (p=.03), milk intake 70.2% vs 44.4% (p=.03)	
Olson 2009	Quasi-experimental	Average number of risk that patients:		No control (not randomized)
		- wanted to change	1.2 risks [SD=1.76]	
		- wished to discuss	0.8 risks [SD=1.46]	
		Average number of patients:		
		- being ready to change risk	43.6%	
Phillips 2014	Cross-sectional	- wanting to discuss risk	34.3%	
		Cancer screening: adherence to risk-based recommendation/specialist consultation (after 6 months follow-up period)	NS	Active control (randomized)
Rubinstein 2011	Comparative: risk-tailored/generic preventive messages	Up-to-dateness of measure of:		No control (randomized)
		- blood glucose and blood pressure levels	NS	
		- cholesterol level	OR=0.34; 95% CI [0.17-0.67]	
Ruffin 2011	Comparative: risk-tailored/generic preventive messages	(after 6 months follow up period)		
		Provider identification of at least 1 of 3 behavioural concerns during visit, among adolescents screened positive before visit, with help of tool report	68% vs 52% in control OR=2.94; 95% CI [1.81-4.76] (p<.001)	Control (randomized)
Stevens 2008	Experimental	Patients receiving ≥1 maintenance reminder	396/974	Active control (randomized)
		Patients receiving recommended:		
		- mammography	48.6% vs 29.5% (p=.006)	
		- influenza vaccinations	22.0% vs 14.0% (p=.018)	
		- other screenings	NS	
Wright 2011	Experimental	(after 60 days follow-up period)		
		Patient reporting discussion occurred for:		No control (not randomized)
		- breast/colon/ovarian cancer risk	22.7% (n=48)/30.5% (n=113)/9.0% (n=19)	
		- thrombosis	9.5% (n=35)	
		- seeing a specialist	22.2% (n=82)	
Wu 2013	Cross-sectional	- lifestyle choice	51.9% (n=192)	

Impact of PGHD collection on the quality of data available at point of care (Table 2.C):

Among 12 studies that analysed these outcomes, 8 were comparative, but only 2 were controlled. Murray et al. (2013)(62) analysed the *completion* of the family history section in medical records within 30 days, depending on whether the patient had the opportunity to use the following devices: portal, laptop, phone voice script and control. Their findings demonstrated a better data collection with portal: 23.1%, OR=16.40, 95% CI [6.10– 44.06] (p<.0001). Similarly, Baer et al. (2013) (42) assessed a close outcome: positive cancer family history collection with laptop (OR=4.3, 95% CI [1.2–15.7] (p=.03)). With uncontrolled protocols, Arsoniadis et al. (2015)(41) assessed a portal ability to collect history of *meaningful utility*, judged by independent rater, with 18.4% for medical history and 11.3% for surgical history, among 50 patients; Wu et al. (2014)(85) assessed ability of the tool to improve *quality of pedigree* available to provider (99.8% (1182/1184) vs <4% at baseline). Other studies assessed mainly *disclosure* rate comparatively to other data collection modalities (with results of inconsistent significance) and *sharing* rate of data from patient with physician.

Table 2.C – Impact of PGHD collection on the quality of data available at point of care:

Author, Year	Study design	Key endpoint (period of follow up before assessment)	Results	Control group (randomization)
Arsoniadis 2015	Quasi-experimental (pre/post)	New patient-entered history of meaningful utility (independent rater checked granularity/evidences in chart)	On 50 patients: - medical history: 18.4% (80/435) - surgical history: 11.3% (26/231)	No control (not randomized)
		New documentation in the EHR of a positive family history of cancer	2.0 % vs 0.6 % (p=.02)	
Baer 2013	Quasi-experimental (pre/post and here/elsewhere)	Association with tool use (30 days after the visit)	OR=4.3, 95% CI [1.2–15.7] (p=.03)	Control (not randomised)
Bajracharya 2016	Quasi-experimental (pre/post)	Patients sending care proxy information: - for the first time - to update EHR information	78/99 (78.8%) 61/101 (60.4%)	No control (not randomized)
Harrison 2003	Cross-sectional	Detection rate of at least one risky behaviour	95.8%	No control (not randomized)
Mangunkusumo 2005	Comparative: internet/ paper-and-pencil	Adolescents disclosure rate differences	NS, except for the item “having sufficient number of friends”: OR 0.36, 95% CI [0.17–0.77] (p ≤ .01)	No control (randomized)
Murray 2013	Comparative: portal/laptop/phone voice script	Patients with new documentation of any family history in EHR, positive or negative; Association with data collection modality (after 30 days follow up period)	Portal: 23.1% (28/969); OR=16.40, 95% CI [6.10– 44.06] (p<.0001) Laptop: 20.3% (67/969); OR=14.23, 95% CI [5.60– 36.17] (p<.0001) Phone: 7.5% (16/969); OR=4.37, 95% CI [1.53– 12.48] (p=.0059) Control: 1.7 % (5/969); reference	Control (not randomized)
Paperny 1990	Comparative: computerized/ paper-and-pencil	Detection rate superiority	high use of cigarette (p<.03)/marijuana (p<.03) problems at home with family (p <.001) often sad, upset or unhappy (p<.007) would like contraceptive (p<.001)	No control (randomized)
Probst 2008	Cross-over: computerized/ face-to-face/ paper-and-pencil 3-day diary	Correlation of diet assessment	Computerized/paper-and-pencil: r=0.16 to 0.52 Computerized/face-to-face: r= -.02 to 0.51	No control (not randomized)
Skinner 1985	Comparative: computer/ face-to-face/ paper-and-pencil	Collected data about toxic consumpt.: patterns / multivariate analysis	NS	No control (randomized)
Thompson 2007	Cross-sectional	At-risk identified children e.g. uncontrolled asthma	373/712 (52%) 49/56 (87%)	No control (not randomized)
Turvey 2012	Cross-sectional	Patient reporting to have shared their data about medications/supplements	30% (n=5490)	No control (random sample)
Wu 2014	Quasi-experimental (pre/post)	Pedigrees including all quality criteria: - for at least one relative - for at least 40% of relatives	99.8% (1182/1184) vs <4% at baseline >60%	No control (not randomized)

DISCUSSION

This review analysed the usefulness and impact of interview PGHD collection in primary care. None of the reviewed studies demonstrated a positive effect on morbidity or mortality, neither on patient quality of life (*Tables 2.A.a, 2.A.b*).

However, computerized data collection was often more efficient than face-to-face data collection (Murray et al., 2013 (62), Baer et al., 2013 (42), Arsoniadis et al., 2015 (41), Wu et al., 2014 (85)) or at least as efficient as paper-and-pencil data collection (Probst et al., 2008 (70), Paperny et al., 1990 (66)) modalities, in various situations.

Several authors highlighted that computerized tools might improve data collection. A positive impact was reported for the following health priorities: symptoms detection (Ahmad et al., 2009 (38)), screening uptodateness (Nagyalkaldi et al., 2012 (63), 2013 (33)), Wright et al., 2011 (83)), risky behaviours (Stevens et al., 2008 (77)), detection of violence in the couple (Ahmad et al., 2009 (38)), elicitation of change based on risk assessment/perception (Acheson et al., 2010 (37), Phillips et al., 2014 (68), Jones et al., 2011 (57)).

A large majority of patients and clinicians reported that such tools were useful -whatever the question asked- (*Tables 2.A.c, 2.B.a*) with better perceived encounter quality (Rogaush et al., 2009 (72), Goodyear-Smith et al., 2013 (55), Fothergill et al., 2013 (52), Poon et al., 2007 (69), Wald et al., 2010 (81), Wu et al., 2013 (84), Nagyalkaldi et al., 2012 (63), Chisolm et al., 2008 (46), Schnipper et al., 2008 (74)), enhanced patient-centeredness (Nagyalkaldi et al., 2012 (63), 2013 (33)) and more relevant topics discussions (Barr et al., 2017 (44), Olson et al., 2009 (65), Ahmad et al., 2009 (38), 2017 (39), Wu et al., 2013 (84), Forjuoh et al., 2014 (51), Geller et al., 2008 (54)). Thus, it might contribute to improve patient healthcare.

Considering that various populations were studied, in different countries, healthcare organizations, and socio-cultural environments, that the analysed studies were performed on almost five decades, for a wide range of data types and with various computerized systems, the reported results appear promising on various intermediary endpoints.

The strength of this review was the wide and cross-sectional focus on primary care. To our knowledge, it has no equivalent. There has not been any review on interview PGHD collection for 15 years (87). Moreover, Bachman et al. (2003)(87) did not focus on primary care. The white paper of RTI International (29) cited few studies reviewed here, as examples. A thesis (88) reviewed primary

cares patients' questionnaires but was limited to data collected located in waiting room and not focused on computerized tools.

Our review also has limitations. The first one is related to the selection of the studies that were reported in this review: a remaining question is whether we might have missed relevant publications. The results were deliberately limited to Medline literature and were dependant of publication bias. Studies selection process was imperfect, the Pubmed request was noisy and not comprehensive. The MeSH indexation appeared inaccurate and many articles were added "by hand". Our review focused on a process, whereas MeSH terms often focused on materials (systems, data). Moreover, PGHD terminology is recent: the corresponding MeSH term was created in 2018 (89).

A second limitation is related to the selected studies, which may have biases: 1) a *selection* bias: patients were often self-selected, with attrition, small sample size, mainly in USA, often in centres where health providers may have participated to the design of tools and were more involved; 2) *assessment* bias: impact of data collection was assessed with limited follow-up, with sometimes questionable scales, many studies used research assistants to welcome/help patients as well as interventions to optimize tool usage (advertising, incentives, ...) and 3) *causality* bias: patients' satisfaction with the visit remains of uncertain imputability, with potential confusing factors (due to content or container of the encounter? More focused/in-depth exchange? Extra-time for clinicians? Preparedness of patients? Technophilia?) and possible nonspecific *intervention effect* (inconstant control group comparison).

Other limitations were the following. Even if the selection process involves two researchers, the articles were analysed by only one reviewer (FB). The assessment of a system could be splitted into multiple articles (one reporting the design, another one assessing the feasibility, a third reporting the data collection), leading to confusion when the same tool was assessed by different papers. Last but not least, the heterogeneity between the studies is a barrier to find convergent evidences. It is often uncertain whether the availability and interoperability of the systems would allow implementation of the system into usual daily practice.

The process we investigated in this review is complex and disruptive. It implies lot of adjustments in usual workflows, with many different possible implementations. If there is a common core (presented in *Appendix 3*), contextual specificity should not be ignored (90).

The challenge is to measure what is happening at the end of a long process, that begins with data collection, through how it is interpreted and influences decisions, until these are put into practice and relevantly impact patient health (see *Appendix 2* for explanations). This needs a long follow-up period.

Some features like messaging could increase efficiency of PGHD (91). Computer adaptative tests (92) and advanced algorithms enable to perform advanced data analyses.

A main issue related to PGHD collection would be to collect more data and to improve data collection quality (93). Another issue is to co-engage patient and clinician (50) to develop a cooperative partnership, based on patients empowerment. On the one hand, digitalization could be viewed as a pitfall. On the other hand, the computer media might be an advantage in the patient-physician relation and might act as a catalyser along the care course: by preparing the patient for care, by clarifying patient preferences, by eliciting in-depth discussions. Information technologies and communication are probably interacting in a complex manner (94). Taking decision based on uncertainty, subjectivity and complexity is of clinician prerogative (95,96) and is much more than checking computer work. Computer is charged with systematic tasks: to memorize, to calculate, to perform repetitive checking, comprehensive screening, etc. as detailed by Bachman et al. (2003)(87).

Current major health issues include digital and social inequities, with related computer- and health-literacy issues. No strong evidence was found in this review to bridge these gaps, but the studied tools did not seem to neglect deprived populations (even if it was not assessed as an outcome, several studies took places intentionally in centres located in deprived area). Adaptative and multimedia nature of computerized interface could even be a way to design more appropriated interface (language, font size and colours, wording level...). Notably for surveys purpose, adjoining an audio component (A-CASI) seems helpful for older (97), severe mental ill (98), low-literate (99) or visually impaired (100) people, school age children (100) and adolescents (100,101). Transposition of traditional questionnaire seems feasible (102). Wide uptake and acceptance of new technologies will help (103). By freeing extra-time for clinicians, they may support patients more equitably. Also, computer may screen for low literacy with a set of questions (104). E-health action levers in this field are to investigate (105).

There are many specific issues related to PGHD collection in primary care: the wide scope, the importance of behavioural information, patient unequal concern and involvement in health priorities. Secondary uses (106,107) of PGHD (e.g. for research or monitoring healthcare) are made easier, raising important ethical issues. This question is beyond the scope of this review.

Finally, these inconclusive results have to be considered in a broader context: the lack of studies in primary care, the questioning digital cost-effectiveness (108), the diseases screening related issues (opportunistic vs systematic) (109), the complexity of mental health care, the challenging assessment of the "quality of life" outcome (110), interviewing methodology (111) etc.

CONCLUSION

This review did not conclude that computerized interview PGHD collection would have clear benefits. Promoting implementation of PGHD collection into daily practice appears premature. Major issues should be addressed: technical interoperability (need of open standards), semantical interoperability, privacy concerns for highly sensitive data. Crossing this bridge will need to focus on workflows and to understand needs of patients and those of clinicians (112).

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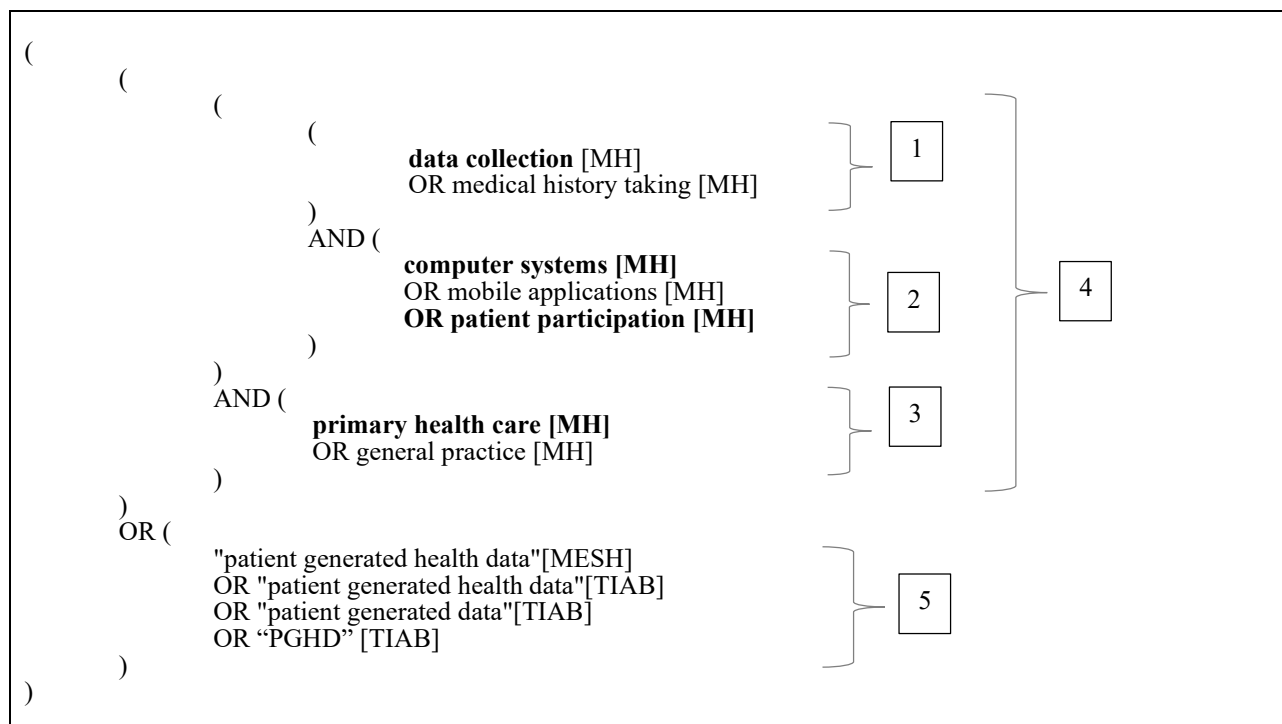
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APPENDIXES

Appendix 1 – Medline request explanation

The Medline request used in this review was as follow (indented for better readability):



Legend:

No. 1 = the fact to collect data: includes notably “Patient Reported Outcome Measures”, “Interviews as Topic”, “Surveys and Questionnaires”, “Health Records, Personal”, “Patient Portals”, “Patient Generated Health Data”, etc.

No. 2 = the manners used to collect data: notice that the MeSH term “Computer Systems” includes the terms “Microcomputers”, “Smartphones” and “Internet”. “Patient Participation” was used to find studies that tacitly include computer usage. “mHealth” was not included because it refers to “Telemedicine” according to the MeSH, related to remote health delivery, which is different of our purpose.

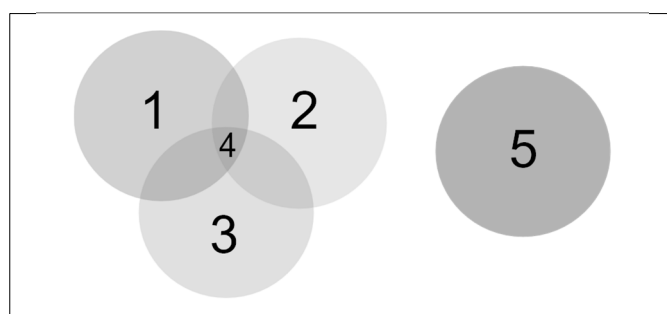
No. 3 = to focus on primary cares and general practice setting (no filter on pathology). Includes “Family Practice”.

No.4 = No.1 AND No.2 AND No.3

No. 5 = “Patient Generated Health Data” : this MeSH term was created in 2018, so it’s too young and little articles could have been tagged with it. This part of the request was not restricted to primary cares on this term because of little number of results (articles were screened by hand on this criteria).

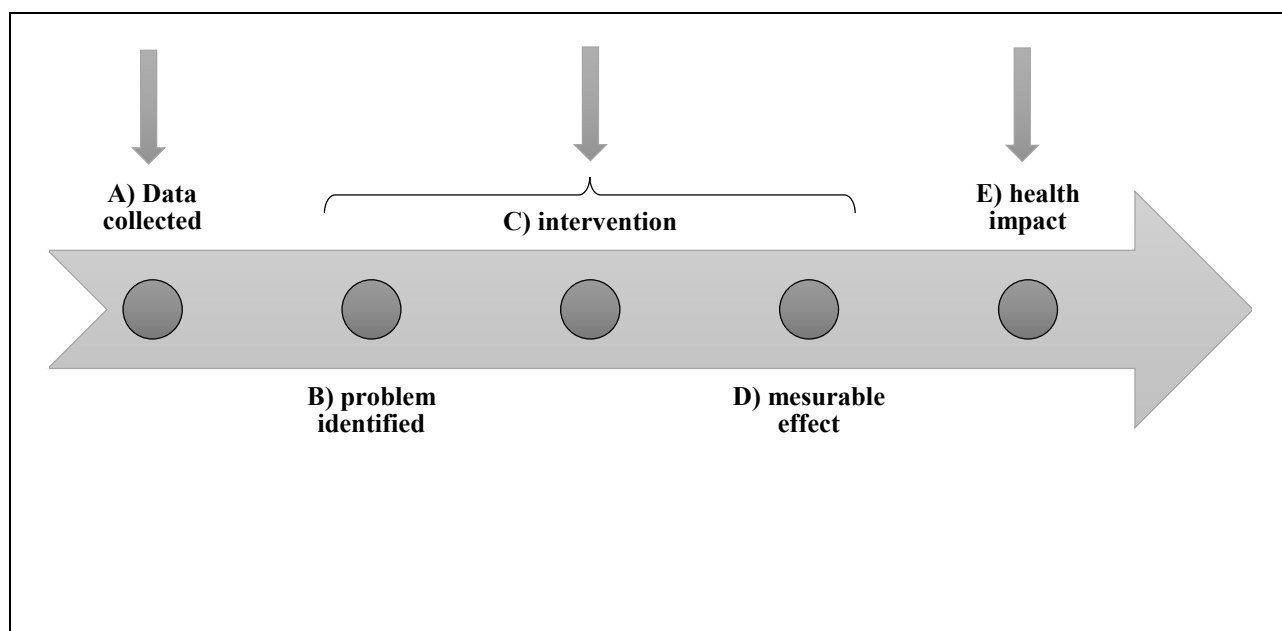
Total results = studies in No.4 OR studies in No.5.

The Euler diagram illustrates and explains how the equation works:



Appendix 2 – Assessment of usefulness

Usefulness assessment were categorised in this review. To explain this breakdown, let us look at steps that occur from data collection to health improvement:



Legend:

A) Fact to have better data available(of enhanced quality : more accurate, more updated, more comprehensive ...).

B) Further assessment or intervention indicated: health risk estimated higher than average, preventive procedure not updated, positive screening result ...

C) Intervention decision, intention and execution.

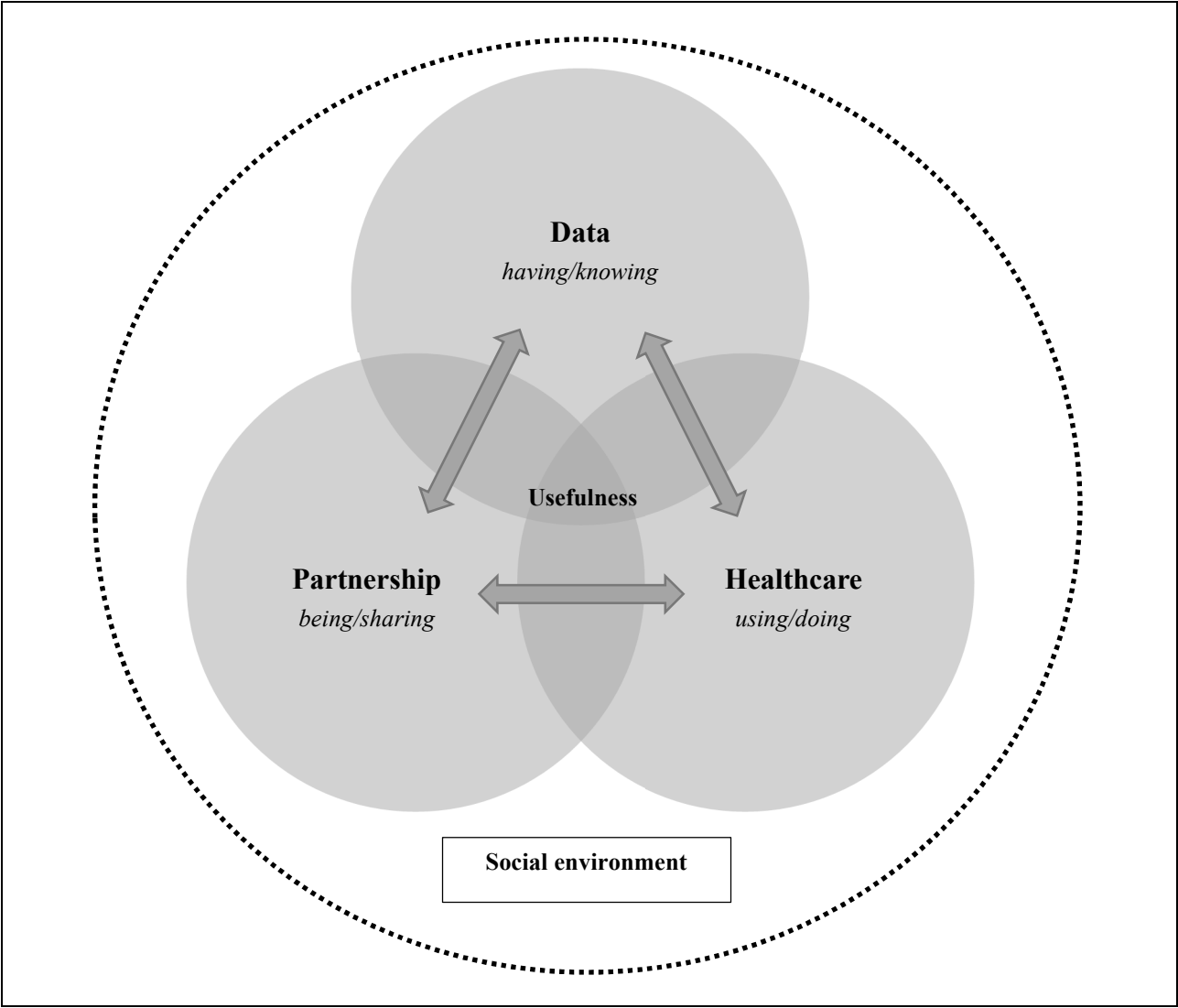
D) Impact on intermediary endpoints as measured or from patient/provider point of view; Including effects on the care course and on clinical relationship.

E) Mortality or morbidity impact assessment as measured or estimated.

All this steps measure ability of a tool/process of care to enhance quality of healthcare.

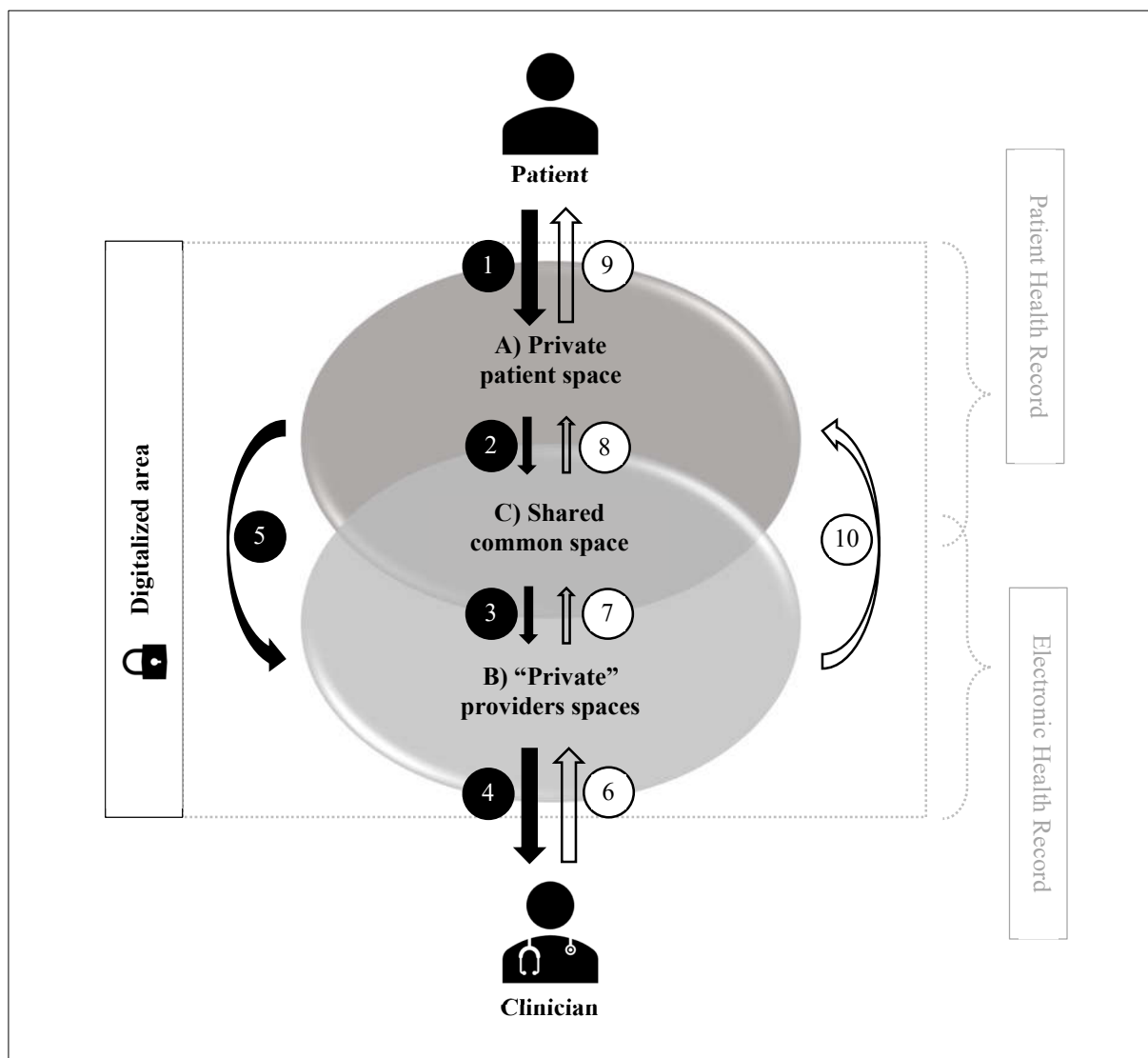
There is a chronological consideration, but also a consideration about the quality of the endpoints: the farthest assessment from data collection giving the strongest endpoint, but often most difficult to observe (it requires long follow-up period, involving many confusing factors ...).

The next diagram details assumed interactions between the dimensions assessed. Usefulness (for patient) in the centre, needs a conjunction of this dimensions, with overlapping limits (cares generates data, relationship can be itself therapeutic, data are collected with relation in mind ...), in interaction (relationship favours data collection and care, data use involves relationships and cares ...). Moreover, these dimensions should be considered inside the socio-environmental setting. Possibly that all is linked, and for example a relationship / morbidity enhancement could encourage data collection, with a hope for a self-sustaining process after priming, and possibly inertia and synergy phenomena? These are hypothesis.



Appendix 3 – Synthesis of systems and workflows

3.1 Systems



Multiple system architectures were described in this review. Getting rid of human-machine interface and underlying system organisation (data storage location, networking, multilayer software ...) enables to consider the flow of data that are clinically significant, conceptualized in a unified and generalized way, to give an overview of computerized PGHD systems most encountered.

Systems described by studies in this review can be assimilated as flows of data between three *digitalized* and *secure* spaces with different *access rights* (notice: numbers, referred between hooks, do not refer to chronological order):

Privates spaces:

- A) Patient's one is commonly called the Personal Health Record (PHR), on which he can (No.1) digitalize data (with a computer or a smartphone, on a website or an application ...). In its minimal presentation it can just be electronic questionnaires. As all data collected by patients are not intended to be known from providers, patients frequently have space devoted to self-management (making it possible to store data in an understandable look with his own words, classification, etc.).

- B) Clinician's one is typically "the" Electronic Medical Record (EMR) software, containing (No.6) clinician's notes, and often integrated lab results, reports from specialists and hospital ... In most systems, patient has not a direct access to the his entire EMR, that is the reason why it is called "private". But in France, EHR content of the patient belongs to him, the doctor is only the depositary, responsible of its management.

Exchanges can be performed between both private spaces in two ways:

- *Directly* (No.5 and 10): it is like messaging, or via a questionnaire on a webpage completed and submitted each other. Patient and clinicians who send data to each other lost ability to modify them: it is *static* data. They may keep a *copy* (so creating a second instance) of what they submitted. Data are integrated by clinician (No.5) into clinician's private space, or by patient (No.10) into patient's private space, to work on it after *review* (e.g. : patient gave smoking information: "no", but during visit the physician assesses that patient smokes 5 cigarettes per week so updating smoking field in the EMR). Private space may keep trace of data history (value, date, author ...).
- *Indirectly* (No.2 and 7): via the shared space, like a "blog" page on which each one can put data to be viewed/picked up (No.3 and 8) by each other. It is *dynamic* data: patient or clinician gives access to each other to the *container*, but *content* can change (with possibly history), so value of data have to be copied if traceability is required.

Shared space: C) is not just a buffer, it's a real *hub* for a dynamic synthesis of important elements according to patient and his providers, unlike private spaces that are more workspaces and archiving spaces. Shared space can so be considered as a part of the two (or more) private spaces, or a common mutualised space between patient and provider in a more balanced way (typically conceived as a centralised separate server ("cloud") for permanent access warranty, it can also be a technical part of PHR or EHR systems, but distributed architecture or even peer-to-peer systems are also possible for example).

Notices:

On a technical point of view: mode of communication described here is *asynchronous* (like messaging: message can be notified in real time but is read at a different time and does not require an encounter; unlike chatting/telephone call that is synchronous, like remote consultation systems).

Patient interacts usually with several providers (family physician, specialists, paramedical, biological analysis laboratory...), which brings a higher level of complexification not represented here to avoid to overload the diagram.

The direction of the flow of data studied in this review was from patient to clinician (from No.1 to 5). But patient had often received data *before*: prepopulated/prefilled forms (with e.g. last date of immunization/screening test), with data to review and to send back. And patient could also receive data *after* data collection: automated report, clinician feedback Provider and patient can so give data to each other by direct transmission ("*private*" exchange: for example for data not to be known from all providers) or sharing ("*public*" exchange: if data are important to all providers). It is interesting to look at the *circular* flow of data in the system, with renewal capabilities.

This relative apparent simplicity hides complex development process, with well-known issues related to medical informatics:

- Technical interoperability between different frameworks: cumbersome data exchange protocols, proprietary software related issues ...
- Challenging linkage between different databases, especially of different data ontologies and granularities. Shared space could facilitate reconciliation because common between both private spaces.
- Keeping systems user-friendly, with mixed comprehensiveness, traceability and flexibility, without compromising access rights management security.
- Balancing data input methods: from ease and freedom of plain text to semantic enrichment of structured fields and coded fields.

To go deeper:

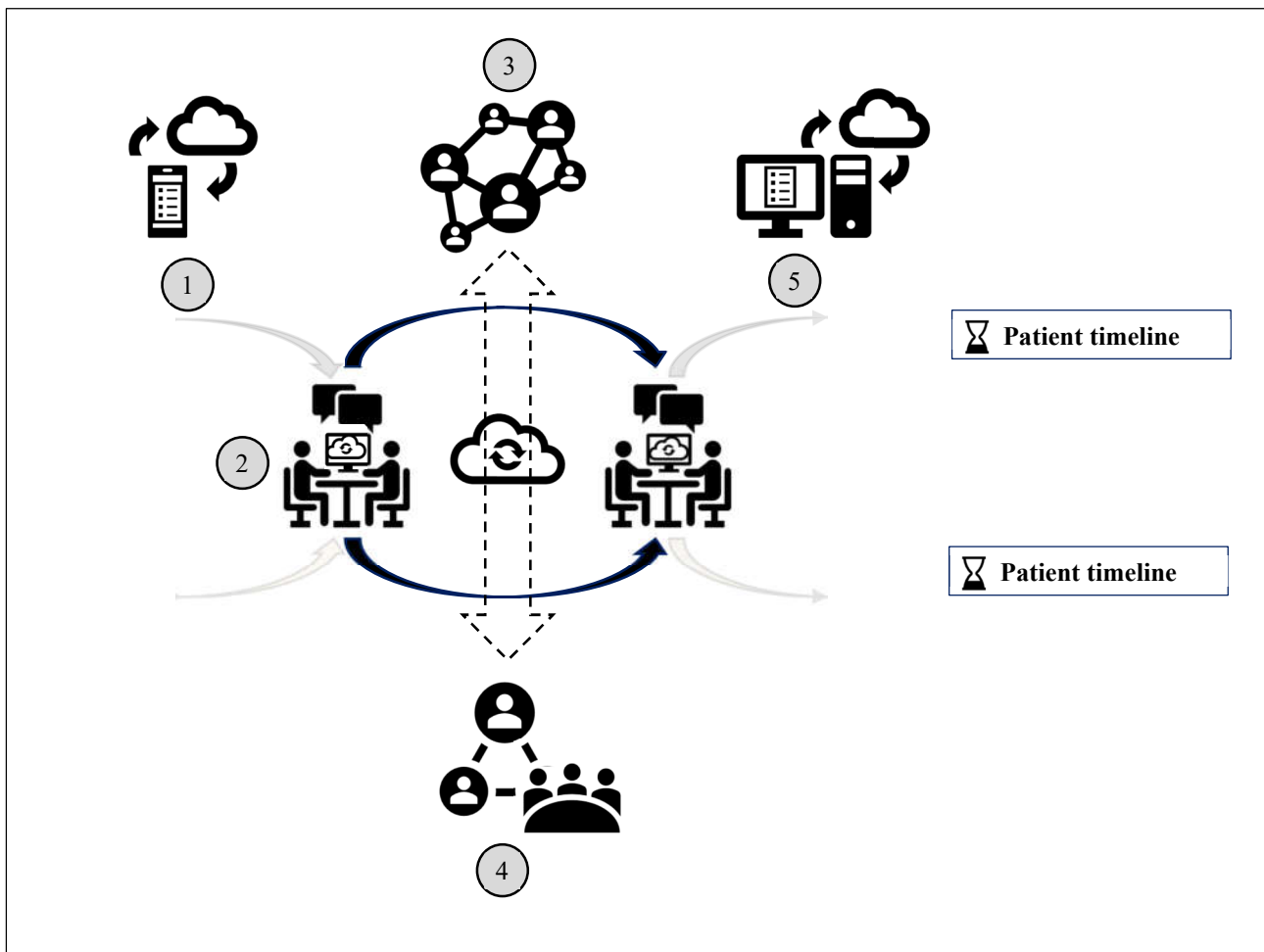
Data are stored in databases. So data are assimilated to “*fields*” (the *container*), assigned with variables *values* (the *content*), linked to other associated information making sense to value (properties often called *metadata*: type, author/maintainer, access rights, dates of creation/modification, values history, context of capture, display patterns, units for numbers ...). Thus, present value is only a small part of “the” data. For example: “3” is the present value of the field “number of cigarettes per day”; It would be interesting to have associated information like: who entered this number, when, in which context, and the value history ... If consulted by a health professional, it would be interesting to show also an estimate of the consumption in pack-year, what may be confusing for patient who will probably prefer a cursor on a scale indicating how much he smokes currently compared to past times, or an histogram ...

The more data semantic is accurate (said of “fine granularity”, determined by properties and database’s fields splitting), the more value can be reused to perform calculation, and submitted to algorithm to help clinical processes. But the more granularity is fine, the more data input is constrained. For example: medical history could be entered: 1) in *free text box*: unstructured plain text, ease to enter but unusable as is by algorithms. 2) In *structured field*: input restricted (e.g. restriction to one history per line, requiring date and status (active/inactive) to be validated...). In this case, data are more difficult to enter but more usable by computers: a linkage can be semi-automatically done between the history line and another part of the record (e.g. a report from a specialist) 3) In *coded fields*: input limited to select an item in a list (e.g. a disease in classification list/tree). Search can be unpleasing, but it enables to automatically establish linkage (e.g. with treatment).

Probably that the use of these three types of fields must be mixed and balanced. Input help are progressively implemented: free-text analysis to detect and assist coding, “intelligent” search when typing ... Systems should also avoid instances multiplications, that brings update issues (if a data is stored in 3 locations, then a process of synchronization has to be developed, with conflicts management requiring user interventions).

One should keep in mind the well-known engineering principle: the more a system is complex, the more issues are likely to happen, the more a system is powerful, the more issues may be of importance. As needs of patient and providers are different, the iterative refinement development with their *participation* is the rule. Placing patient in the centre of this system is more comfortable for healthcare providers, to be discharged of some stains, but puts a heavy *burden* on patient. Sharing and negotiating burden and responsibility is probably the way but would be hard to balance in practice.

3.2 – Workflows



Given such systems, many workflows are possible. Since reviewing data entered by patient is not the only subject of the subsequent visit (even if collecting these data aimed at preparing this visit), it is just possible to give a simplified overview of how systems can be used, to explain how they were assessed in this review. The diagram tries to present the typical workflow in a longitudinal and integrative way.

- (No. 1) Patient starts to enter in the system data of his choice:

- according to: which form he was given access, his preferences and priorities, what he agreed with the provider during preceding encounter ...
- possibly previously gathered and digitalized on another system/medium
- with smartphone, tablet/laptop/desktop computer ...
- real-time adapting questionnaires are enabled with skip-patterns (next questions asked depends on response to previous) and even computer-adaptive test.

Eventually, computing and analytic algorithms are applied to these data, and reports delivered to patient and provider. With possibly alerts and reminders generating if needed (electronic messaging, EHR-integrated prompting ...).

- (No. 2) Then in-person encounter takes place. It's time and place to share thoughts and feelings, to look at tests results, to physical examination, to agree about cares (screening test, treatment ...), objectives and planning. Patient-reported data and computed results can be reviewed and discussed, integrated in clinical approach, but is only a small part of the encounter, and needs to be spread over time.

- (No. 5) Then patient continues to review data given by provider (and possibly provider reviews data given by patient, which could bring problem of workload according to workflow and amount of data collected).

If communication takes place synchronously between physical encounters, it deals with remote consultation and telemedicine, which is not the purpose here. But between two encounters, (No. 3) patient is in relation with many peoples (family, other providers, ...) and (No. 4) provider too (specialists/paramedical in charge with same patient, mutlti-disciplinary staffs ...) which brings a higher level of complexity in this typical workflow, inducing asynchronous data exchange between encounters ... It can be imagined that some health professional could help patients to enter data in the system, in order to facilitate encounter. This task could be a part of growing health mediation activity. Fact to collect data is important too, not just data values.

Sample hypothetical workflow:

To better understand how these systems can be used, let us look at an example:

The Patient P. sees doctor D. for a antihypertensive treatment refill. They both agree that P. will respond to a general questionnaire before next treatment refill appointment.

This questionnaire is about toxic consumption including smoking and alcohol, anxiety and depression screening, heart disease screening, tetanus immunization... And enables patient to indicate topic to discuss. P. populates the questionnaire at home, or in waiting room with his own computer or smartphone. He receives a report with possible automatically tailored recommendations.

At next visit, for medication refill, D. is prompted that P. filled the questionnaire. He can see results in a special section of the EHR. D. sees that P. smokes again, is not ready to stop now, but would like to talk about. D. sees also that P. sometime exceeds the maximum recommended consumption of alcohol during a week; P. was informed about that by the report but doesn't want to discuss about that. D. sees significative anxiety level with sleeping disorders. P. selected sexually transmitted diseases and colon cancer screening as topic to discuss.

First D. can establish a link between lifestyle of patient and his uncontrolled elevation of blood pressure.

D. verifies the date of last and next tetanus immunization on card brought by patient as it was suggested by the report, and D. sets a reminder that will trigger in D. and P. interfaces.

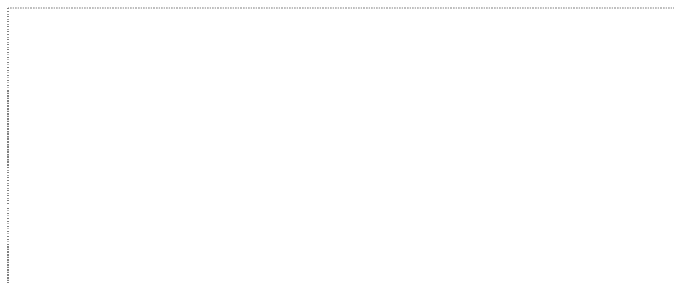
About colon cancer screening, they plan to discuss it again with familial history filled by patient with a specific module: D. sends a request that P. will see in his PHR.

About sleeping disorders, D. learns that P. sees a psychologist. So, P. enters this element in active problems list. P. prefers avoid medication. They agree to discuss about these disorders in 6 months based on a new electronic assessment.

About sexually transmitted diseases, after explanations, P. is reassured but they plan to do a test on next blood test in 3 months.

Nothing is really new in this visit description. Even if description is centred around documentation in EHR, D. learns previously unknown concerns. It is hoped that so freed time would be allocated to relationship, notably to consider patient individuality. Human warmth in not computerizable ...

Vu, le Président du Jury,



Professeur Rémy SENAND

Vu, le Directeur de Thèse,



Docteur Cédric RAT

Vu, le Doyen de la Faculté,



Professeur Pascale JOLLIET

Titre de Thèse : L'interrogatoire informatisé du patient en dehors du temps de la consultation en soins primaires : une revue de la littérature à partir de Medline.

RESUME

Contexte : Recueillir des données sur la santé et les comportements de santé en proposant aux patients de compiler ces informations directement dans des outils informatiques pourrait aider les cliniciens, dès lors que cette information est ensuite accessible au clinicien dans son logiciel métier. Des systèmes permettant ainsi de collecter les informations de l'interrogatoire de façon informatisée existent, mais l'existence d'un bénéfice réel pour les patients ne semble pas clairement établie.

Objectif : analyser si le fait de collecter des données d'interrogatoire saisies par le patient présente une utilité, et avec quel impact.

Méthode : il a été réalisé une revue systématique de la littérature à partir de Medline sans limite de date.

Résultats : Parmi les 2345 études initialement identifiées, 52 ont finalement été analysées. Aucune d'entre elle n'a démontré un impact positif en termes de morbidité ou de mortalité, ni en termes de qualité de vie. Cependant, la collecte de données saisies informatiquement par le patient était fréquemment plus efficace qu'en face à face, et au moins aussi efficace qu'une collecte au format papier, dans diverses situations. Plusieurs auteurs ont mis en évidence que les outils informatisés pourraient améliorer la collecte des données. Il a été observé un impact positif concernant des problématiques de santé prépondérantes : les comportements à risque, la détection des violences conjugales, la motivation au changement par l'estimation des risques. Une importante majorité de patients et de cliniciens ont trouvé ces outils utiles

MOTS-CLES

Données générées par le patient ; Entretien clinique médical ; Systèmes informatiques ; Ordinateurs ; Soins primaires ; Revue systématique de la littérature.