Eliciting and Confirming Data, Information, Knowledge and Wisdom in a Specialist Health Care Setting: The WICKED Method

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Abstract—Healthcare is a knowledge-rich environment. This knowledge, while valuable, is not always accessible outside the borders of individual clinics. This research aims to address part of this problem (at a study site) by constructing a maximal data set (knowledge artefact) for motor neurone disease (MND). This data set is proposed as an initial knowledge base for a concurrent project to develop an MND patient data platform. It represents the domain knowledge at the study site for the duration of the research (12 months). A knowledge elicitation method was also developed from the lessons learned during this process - the WICKED method. WICKED is an anagram of the words: eliciting and confirming data, information, knowledge, wisdom. But it is also a reference to the concept of wicked problems, which are complex and challenging, as is eliciting expert knowledge. The method was evaluated at a second site, and benefits and limitations were noted. Benefits include that the method provided a systematic way to manage data, information, knowledge and wisdom (DIKW) from various sources, including healthcare specialists and existing data sets. Limitations surrounded the time required and how the data set produced only represents DIKW known during the research period. Future work is underway to address these limitations.

Keywords—Healthcare, knowledge acquisition, maximal data sets, action design science.

I. Introduction

THIS research had two aims: firstly, constructing a maximal MND data set that could be used as an initial knowledge base for an MND patient data platform (currently under development); secondly, constructing the lessons learned during the first aim into a knowledge elicitation method. To achieve the first aim, knowledge and wisdom (KW) acquired from healthcare experts at a specialist MND clinic was collated with data items and information (DI) from sources, including relevant literature and an existing registry core clinical data set. From this collated DIKW, a maximal (or largest possible) data set was extracted.

As no end-to-end knowledge elicitation method was found in the literature, the second aim of this research was to formulise the lessons learned during the process into a DIKW elicitation method that could be useful for the healthcare domain. The method's name is WICKED, an anagram of the words: eliciting and confirming data, information, knowledge, wisdom. This title references the concept of wicked problems, which are complex, challenging and have no stopping rule [1], [2]. This research is part of a larger project developing an MND patient

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data platform.

A research question was developed to achieve the stated aims: "What are the benefits or limitations of a healthcare-specific knowledge elicitation method?" This question was further distilled into three linked objectives which are described below. Using an action design research (ADR) approach [3], each objective builds on outputs from the previous one, and each objective corresponds to a stage of an ADR approach.

- Objective 1: To confirm and scope the problem. Relates to ADR Stage 1: Problem Formulation.
- Objective 2: To build and evaluate a knowledge artefact that could address the confirmed problem. Relates to ADR Stage 2: Building, Intervention and Evaluation.
- Objective 3: To extract lessons learned from the process and formalise them into a knowledge elicitation method that can be evaluated. Relates to ADR Stage 4, Formalisation of Learning.

ADR Stage 3 is concerned with reflection and learning, processes which permeate the entire research process and are therefore not represented by a separate objective.

The research hoped to make two contributions – practice and knowledge. The practice contribution is in the form of a project artefact - a maximal data set. The knowledge contribution is in the form of a healthcare-specific knowledge elicitation method – the WICKED method.

Following this introductory section, the paper is structured as follows. Section II discusses the background of the research. Section III discusses related work (outputs from a literature review). Sections IV-VII discuss the methodology used – ADR - and its application to this research. This is followed by an evaluation of the knowledge elicitation method (at a second healthcare site) in Section VIII. Research findings and discussions are in Section IX. The paper finishes with a conclusion in Section X.

II. Background

A co-creation group (n = 11) was formed for the project that comprised technical and clinical experts. Technical experts were from a single academic group, and expertise included computer science, health informatics and knowledge engineering. The clinical experts, a specialist motor neurone disease multi-disciplinary team, MND-MDT (the study site), instigated the project. Clinical expertise included medical,

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physiotherapy and research.

A. MND Minimum and Maximal Data Sets

The MND clinic was established in the early 1990s and has accrued a significant body of knowledge on MND and was regarded as experts in the domain. In addition, to journal articles, education and research, another way knowledge was preserved at the study site was through an MND registry managed by a research team linked to the clinic. One purpose of this registry was to understand the disease trajectory at a macro level. The data set used (for the registry) represented a minimum data set (MDS) or core clinical data set. MDSs are a collection of data elements deemed relevant to a specified objective. A primary purpose of an MDS is to standardise data collection and facilitate data sharing on a topic [4], [5]. Clinical experts (at the study site) noted that while the MDS represented an internationally agreed core clinical data set for MND research, it was not representative of all knowledge generated by the experts at the site. For instance, it did not capture details of potential co-morbidities. To capture and preserve any additional MND knowledge that had been accrued at the study site and may be relevant to the larger project, the co-creation team discussed that developing a maximal data set could be important, both as an initial knowledge base for an MND patient data platform and to preserve specialist knowledge.

B. Data, Information, Knowledge, Wisdom (DIKW)

This research will discuss the concepts of DIKW as distinct core concepts within clinical information systems. Building on earlier work by Blum [6], Graves and Corcoran [7] note that data are "discrete entities that are described objectively without interpretation". Information is "data that are interpreted, organised or structured" whereas knowledge is information that has been "synthesised so that interrelationships are identified and formalised". Although Blum [6] or Graves and Corcoran [7] did not include the concept of 'wisdom', later work by Ackoff [8] and Nelson [9] does. The American Nurses Association (ANA) describes wisdom as the "appropriate use of knowledge to manage and solve human problems" [10]. Ackoff [8] describes wisdom as central to the exercise of judgement. While acquiring data and information is comparatively easy, acquiring KW is more complex. A potential reason is that data and information are more easily codified [11], in contrast, KW have tacit dimensions that are more difficult to reproduce. Referring to tacit knowledge, Polanyi [12] noted that we "know more than we can tell".

DIKW are often presented as a pyramid with data at the bottom and wisdom at the top and referred to as the DIKW hierarchy [6]-[8]. Although this allows users to distinguish between the individual concepts, the hierarchy is not without its critiques. For instance, Blum [6] cautioned against viewing each concept in isolation. They propose viewing the hierarchy as increasing in complexity when moving from data to wisdom. However, it should not be assumed that such a progression is inevitable [13]. Despite these critiques, the DIKW hierarchy provides a way to understand the differences between the concepts.

III. RELATED WORK

A literature review was conducted to understand healthcare knowledge elicitation methods and associated strengths and challenges. From 3430 papers, a final number of 27 studies were included in the review. From this review, two broad approaches to knowledge acquisition in healthcare emerged. These can be broadly described as: (1) direct (from subject experts) or (2) indirect (from data sources) (see Table I). Two themes relating to the direct approaches were identified: 'Researcher mediated capture' and 'Digital mediated capture'. Two themes were identified relating to indirect approaches: 'Generated using artificial intelligence methods' and 'Generated from existing data sets'. Although presented as distinct themes, some articles reviewed discuss combining more than one approach when capturing expert knowledge [14]-[18], beginning with researcher mediated capture [14]-[18]. In addition to these themes, three common challenges to capturing expert knowledge emerged: accessing expert knowledge, confirming the quality of knowledge, and continual knowledge capture. Specific issues under each challenge differ, either wholly or to varying degrees, depending on the approach and the context within which they are deployed. For instance, continual capture with direct approaches is more complex when compared to indirect approaches. Methods and challenges are described in greater detail in the following text.

TABLE I
LITERATURE REVIEW THEMES

Approach	Theme/sub-theme	Papers
Direct	Theme 1: Researcher mediated capture	[14], [19]-[25].
Direct	Theme 2: Digital mediated capture Sub-theme 2a: Captured in specified purpose platforms	[16], [17], [26], [27]
Direct	Theme 2: Digital mediated capture Sub-theme 2b: Captured in a virtual community of practice (vCoP)	[28]-[33]
Indirect	Theme 3: Generated using artificial intelligence methods	[15], [18], [34], [35]
Indirect	Theme 4: Generated from existing data sets	[4], [5], [36]-[38]

A. Direct Knowledge Acquisition

Direct knowledge elicitation describes how knowledge is taken directly from subject experts [24]. Two themes identified relating to direct knowledge capture are 'Researcher mediated capture' [14], [19]-[25] and 'Digital mediated capture'. The latter was further distilled into two sub-themes: 'Captured in specified purpose platforms (SPP)' [16], [17], [26], [27] and 'Captured in a virtual community of practice (vCoP)' [28]-[33].

B. Indirect Knowledge Acquisition

Indirect approaches extract new knowledge from previously captured data in various digital sources, including medical records or existing data sets. Two themes were identified. Firstly, the theme 'Generated using artificial intelligence methods' [15], [18], [34], [35] describes the application of artificial intelligence techniques to generate knowledge from source data. Secondly, 'Generated from existing data sets' describes how the construction of healthcare MDS included extracting data elements from sources, including patient records

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or existing data sets [4], [5], [36]-[38].

C. Challenge 1: Accessing Expert Knowledge

Expertise can describe skills, knowledge or abilities across a broad range of activities [39]. Identifying the expert can present challenges, particularly for non-experts or those unfamiliar with the domain and often relying on 'peer-nominations' [40]. Some papers retrieved noted that participants were identified as experts to the researcher and invited to participate based on this, for example, [20], [33]. Others were included due to their membership in a group, unit, organisation, or profession [15], [19], [23], [31], or identified by their organisation for inclusion based on their experience and knowledge [17].

Another challenge identified is the different dimensions of knowledge – specifically tacit and explicit. Explicit knowledge is codifiable and thus easier to share, while tacit is more difficult [11]. Originally introduced by Polanyi [12], the term 'tacit knowledge' refers to that which is personal, hard to articulate or 'we know more than we can tell'. Brown et al. [41] noted there could be difficulty asking experts to recall all they know when aspects of their knowledge are held tacitly and therefore tricky to recall without appropriate stimuli. Furthermore, knowledge can be difficult to access when embodied in people [42], [43], 'routines, processes, practices and norms' [44].

Virtual communities, such as vCoPs, have been muted as a method of capturing knowledge in a digital and, therefore, recordable format [45]-[50]. However, the success of a vCoP is predicated on the participants' willingness to participate and share their knowledge [51]. Challenges to participation include lack of time (to engage), lack of knowledge (on the discussion topic), fear of criticism or reprisal, technological issues and potential impact on reputation [47], [52]-[57].

Studies show a positive correlation between trust and knowledge sharing [51], [58], [59]. Ardichvili [51] noted that two types of trust were important to vCoP members – personal and institutional. Personal trust is based on the first-hand experience of the person. Whereas, institutional is built when members are satisfied that control mechanisms are applied by the host organisation so that posts are protected. Familiarity (through name or personal contacts of long-standing members) helps build trust between members of the vCoP [31].

D. Challenge 2: Confirming Quality of Knowledge

Validation methods discussed in the literature could be broadly grouped into two approaches – expert consensus [21], [22], [24]-[26] and comparison. The latter includes comparisons between pre and post system deployment [23], novice and expert [20] or diagnostic comparisons between expert and system results [14], [27]. A potential challenge noted with these validation methods relates to the differences between individual experts' judgement. For example, in their post-analysis González-Ferrer et al. [27] describe how an event (hypovolemia due to gastrointestinal bleeding) recorded (before the study) in a patient's medical chart prompted experts to review their original guidelines with respect to this. Torshizi et al. [24] note that clinical judgement draws from many factors, including experience. It is conceivable that there could be different recommendations from different doctors for the same case.

Challenges associated with indirect approaches surround the quality of the data, including inaccurate or incomplete sources [14], [18], [25], [27], [34]. In addition to formal documentation systems, knowledge can be captured in informal systems, such as nurse's handover sheets [60], [61]. Along with missing or damaged documentation, studies question the validity of the data captured in nursing notes [18], [62]-[64]. For example, de Marinis et al. [62] reported that only 40% of nursing activities observed (by the researchers) were recorded in the patients' records. Similarly, Thoroddsen et al. [18] found that identified pressure ulcers were only documented in the patients' records 60% of the time. Several studies have cited poor accuracy in data captured [63], [64]. Paans et al. [64] found entries relating to interventions displayed greater levels of inaccuracies, with admission notes ranking as the most accurate by comparison.

E. Challenge 3: Continual Knowledge Elicitation

As healthcare is a knowledge-rich environment, data sets will need to be reviewed at a future point to add new or remove redundant items. Challenges noted relating to indirect knowledge acquisition include the availability of records [14] and the reliability of initial data captured [14], [18], [25], [27], [34]. The continuing presence of human input in the entire process, even indirect approaches, for instance, [17], [18], [26], [34] made continual knowledge elicitation more complex.

F. Summary

The literature provided guidance on how to develop MDS using existing data sets (for example, see [36]) and techniques for eliciting expert knowledge (for example, see [65]). Other methods of researcher-mediated knowledge elicitation described in the broader literature include concept mapping, interviews, observation, and storytelling [66]-[73]. However, no single method was found that addressed known challenges and provided an end-to-end solution capable of integrating DIKW from various sources; addressing this gap was deemed important. The next section describes the ADR methodology adopted and how it was applied in this research to generate a maximal data set relating to MND research.

IV. METHODOLOGY

For this research, the authors applied ADR described by Sein et al. [3] to develop and evaluate the research artefact (maximal data set) and to extract lessons learned during the process to construct a domain-specific knowledge elicitation method. ADR is comprised of four stages: (1) Problem Formulation, (2) Building, Intervention, and Evaluation, (3) Reflection and Learning and (4) Formalisation of learning [3].

The following text describes how an ADR methodology was applied in this research to produce a knowledge artefact and a knowledge contribution (knowledge elicitation method – the WICKED method). Stage 1 and stage 4 of the ADR approach mirror work by Sein et al. [3], whereas the 2nd stage (Building, Intervention and Evaluation) was adjusted, mindful that the priority was not the design of the artefact but the elicitation and

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validation of a maximal data set. Stage 2 draws on work by Mullarkey and Hevner [74]. They discuss evaluation (of an artefact) as a pervasive process rather than a separate stage at the end. In this research, confirmation of the acquired DIKW used to develop the data set was persistent (by consensus and comparison – see Step 4).

V. ADR STAGE 1: PROBLEM FORMULATION

The trigger for this research was provided by the clinical members of the co-creation group (see Background section). As discussed previously, the study site is a specialist MND clinic. In addition to providing clinical care, the site had established a specialist MND registry that had been in use for over two decades. Data for this registry were collected weekly by a clinical researcher based at the study site. This individual was not directly involved in this research. Using specially designed clinical visit sheets, this researcher captured patient data manually from the patient's record. These sheets contained a set of core clinical data items (n = 285) relevant to the presentation and progression of the disease. Once captured on paper, the data items were entered into a digital registry document. One goal of the patient data platform project was to digitise this process so that collection was more streamlined (and to remove the transcribing step).

To prepare for research and understand the study site, the co-creator group discussed various topics, including the disease and its impact on patients, patient referral processes, and the clinic's background (the study site). These topics were developed into a set of infographics and process maps. These were used as communication aids by both the technical and clinical experts. One function of the co-creator group (for stage 1) was to collaborate to scope the research problem and identify any additional requirements relevant to knowledge elicitation research. These additional requirements were identified as the knowledge artefact, knowledge topic and key knowledge roles.

The knowledge artefact, the maximal data set, is a tangible output that has practical uses for the co-creation group. The co-creation team proposed that the maximal data set could use an existing core clinical data (registry data set) set as a data collection starting point. The research would build on this and include additional MND knowledge accrued at the study site by domain experts but was outside the core clinical data set. The purpose of this artefact was an initial knowledge base for an MND patient data platform that was being developed and as a means of preserving specialist MND knowledge. A single research document (SRD) was used as a platform or repository for this data set using a digital spreadsheet.

Eliciting the knowledge an expert has built over their career can be a monumental undertaking, the research focused on a specific topic. This topic is described as the 'knowledge topic'. For this research, the knowledge topic identified by clinical experts surrounds early warning signs of disease progression for an MND patient cohort.

In addition to normal project management responsibilities, four additional roles were identified as relevant to a knowledge elicitation process. These are Holder, Seeker, Reviewer and Gatekeeper. The Holder was a co-creator (clinical expert) who had relevant knowledge to share. Looking for this knowledge was the researcher (Seeker). Clinical experts validated acquired DIKW (Reviewer). In the case of any disputes, a co-creator that is also a subject expert would act as an arbitrator (Gatekeeper). These terms (Holder, Seeker, Reviewer and Gatekeeper) will be used for the rest of this paper as appropriate.

It was proposed that the core clinical data set could be useful for a DIKW collection starting point and a post-comparison measure. The co-creation group meet regularly - 23 formal group meetings and site visits took place across the research period of 12 months. The time required for additional formal contact (such as telephone calls, virtual meetings, or contact by email) or informal contact is difficult to quantify, so cannot be included in the total number of group meetings.

VI. ADR STAGE 2: BUILDING, INTERVENTION AND EVALUATION

ADR Stage 2 is concerned with the building, intervention and evaluation of an artefact. As the focus was on the content of the artefact (DIKW), the 'Building' component of the ADR stage 2 was further distilled into three steps: collect, collate and construct. 'Collate' was further divided into 4 phases. As the artefact was research-focused and not a clinical document, implementation into the clinical context was deemed beyond the scope of this research. Instead, 'implement' and 'evaluate' were consumed into the step 'confirm'. Although presented as sequential, movement across the WICKED method could be forward or backward until no new data items emerge. The output from ADR stage 2 is the knowledge artefact, a validated maximal data set containing relevant DIKW (to the agreed knowledge topic). This data set was constructed into an SRD to organise the data set. These steps and phases are discussed in the following text.

A. Step 1: Collect

In addition to reviewing relevant policies, procedures and literature, a 'role-play' approach was adopted to collect KW from domain experts. The Seeker (researcher, SI), role-playing as a 'new researcher to the study site', asked the Holders to discuss the knowledge topic (early warning signs of disease progression for an MND patient cohort). This approach (role-playing as a new member of staff) was informed by the work of Nonaka and Takeuchi [11]. They describe how tacit knowledge is shared between groups when working together. Knowledge is converted from tacit to explicit when the receiver externalises this new knowledge and articulates it to others. Making use of this exchange, Nonaka and Takeuchi [11] describe a project (developing a bread-making machine) where a member of the development team apprenticed themselves to an expert and was then able to relay what they had learned to the rest of their project group.

The Seeker (SI) was invited to attend weekly clinic meetings (held on-site) by the clinical lead over a three-month period. Opportune questions were put to attending members of the clinical co-creation team. During monthly co-creation meetings at the academic institution, the Seeker (SI) was able to ask follow-up questions or clarify points raised from earlier work.

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As required, additional meetings with specific members of the co-creation team were arranged across both locations (and virtually). Relevant journal articles, policies and procedures were reviewed, and DIKW (relating to the knowledge topic) were extracted.

Data collected were transcribed verbatim onto digital post-it notes and entered onto a digital whiteboard. These included a mix of DIKW, observations, questions or statements. Examples are listed in Table II.

TABLE II
EXAMPLES OF DATA COLLECTED

Example	Type
Clinical scores or measures	Data/Information
Clinical parameters for clinical scores or measures	Knowledge
'make sure the patient has a way to call for help, especially if their normal communication route is diminishing.'	Wisdom
'Observe for signs of respiratory distress.'	Observation
'Does the patient smoke?'	Assessment question
The ethos of the clinic is one of Hope	Statement

These digital post-it notes were referred to as 'expert prompts' as they were the cues or prompts given (to the Seeker) by clinical experts relevant to the knowledge topic. There was overlap between data retrieved from the approaches (study site, group meetings, literature and existing data set review), making it difficult to quantify the exact number of data items retrieved from each. Therefore, they are presented as a single figure. In total, this first phase yielded approximately n = 392 expert prompts.

B. Step 2: Collate

To move from 'expert prompts' to a maximal data set, the collected data underwent a four-phase collation process:
- Phase 1: Topic groups or Consideration groups formed (topic index).
- Phase 2: Review groups to identify appropriate research assessment questions.
- Phase 3: Identifying additional relevant DIKW for each research assessment question.
- Phase 4: Review groups against previously identified categories. These are referred to as 'Everything Categories' and are discussed in this section.

Phase 1

For phase 1, an initial set of 12 topics was extracted from the existing core clinical data set and approved by the co-creation group (as Holders and Reviewers). The purpose of these topics was to group 'expert prompts' together and help manage the volume of data collected. Topics identified included 'Equipment', 'Patient Demographics' and 'Education and Employment'. Not all 'expert prompts' captured fit within these topics.

A decision was made to also include topics from the Activities of living (ALs) framework [75]. ALs is a 12-category nursing assessment framework used to assist nurses in completing a comprehensive patient assessment. ALs categories include 'Breathing' and 'Maintaining a safe environment'. According to Roper et al. [75] ALs "encapsulate all the complexities of living" (p.19). The framework is widely used in clinical practice (including the study site's organisation). The 24 topics identified (from the core clinical data set and AL framework) were merged and duplicates were removed. This resulted in a total of 19 topics identified. These were collectively referred to as the topic index.

Through discussions among the co-creation group, expert prompts collected were assigned to a topic as appropriate. Following this process, several prompts remained unassigned. The group reviewed these unassigned prompts to see if additional topics could be extracted and an additional 14 topics emerged. Additional topics included 'Past medical/surgical history including medications'. Four (of the 14 new topics) were incorporated into the topics index (to give 23 topics). The remaining topics (n = 10) contained expert wisdom and general information. These ten groups were described as 'considerations'. Examples of these consideration groups include clinic ethos, culture, the people (and their problems) in the domain, and the systems connected to the study site.

Among the ten, Consideration group was the one related to expert wisdom. An example of this is: 'always make sure the patient has a way to call for help – especially when they have communication deficits'.

The Consideration groups were reviewed, and relevant data items were extracted where possible. For instance, 'always make sure the patient has a way to call for help – especially when they have communication deficits' generated data items surrounding communication equipment, maintaining a safe environment, communication decline, patient support and referrals. These data items were assigned to relevant topic groups. For example, communication equipment was allocated to 'Equipment'.

Other examples, such as clinic ethos, did not generate data items but did help the Seeker to understand the study site better. Rather than discarding any 'Considerations', a record was maintained as they could have value at another stage of the MND patient data platform project.

Phase 2

Once all prompts were assigned, the topic groups (topic and corresponding prompts) were reviewed in phase 2. Reviewers identified an appropriate research assessment question for each topic. In total, 23 questions were identified. For example, the topic 'All Measures and Scores', which contained 26 expert prompts, was linked to the question: "What measures/scores are used in the domain relevant to the knowledge topic?" Questions were generated through discussions with the clinical co-creation group. These questions were used in phase 3 to review each topic in more detail.

Phase 3

While the initial data collection captured an amount of relevant DIKW to gather the maximum amount possible, each question was individually reviewed in phase 3 (using questions developed in Phase 2). Each question was further explored during group discussions with Holders (from the clinical group)

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using the role-play method described earlier (see Step 2: Collect). Holders were asked to identify the relevant DIKW required but not currently captured to the Seeker to answer the question satisfactorily. The Gatekeeper (the clinical lead) had the final say on what could be included based on their clinical expertise.

This process generated 1,661 data items across the 23 topic groups/research assessment questions. Concerning duplicate data items, as each question was processed individually, some data items, for instance, patient name or date of collection, were included in all 23 groups/questions (as it was relevant to answer each question). It was considered a duplicate if a data item could be asked once but used to populate other incidences (of the same question). Other data items found across the 23 questions relating to medication or co-morbidities appeared to be duplicates but generated different answers depending on the topic. For instance, medication could be different if related to breathing or pain management. Items considered duplicates were removed, leaving a final number of data items of 872. As this was a research-facing document, a decision was made only to include clinical scores/scales outcomes, not the list of assessment questions that feed into the score.

Phase 4

Finally, in phase 4, the 23 Topic Groups and ten Consideration Groups were reviewed, and six high-level categories emerged. These categories are People/Problems, Systems, Governance/Culture, Clinical Signs and Symptoms, Equipment/Medications and Business Processes.

C. Step 3: Construct

In Step 3, the maximal data set identified was constructed into an SRD. This is a spreadsheet, and each tab represents one of the 23 topics identified. It was used in this research to organise the data items.

D. Step 4: Confirm

The maximal data set needed to be confirmed (validated). Rather than confirmation as a single step, as knowledge was collected, collated and constructed, confirmation processes were run concurrently. This approach draws from the work of Mullarkey and Hevner [74]. For instance, ongoing discussions took place with the co-creation group during the collection, collation, and confirmation steps. The collected data were compared to the agreed knowledge base – the existing core clinical data set. To the initial 12 topics identified, a further 11 were added, resulting in a final 23 topics. For a full description of the development of the topic index, see section Step 2: Collate. Other confirmation processes included confirmation by consensus and confirmation by comparison. This pervasive approach helped ensure knowledge collected was valid and relevant to the knowledge topic.

Confirmation by consensus describes achieving group agreement, where the majority rules and the Gatekeeper has the final say (in case of disputes). Expert consensus has been adopted in other projects [22], [24], [26]. The co-creation group discussed the research assessment questions and related data items and was free to add, remove or amend as required. From

discussions, it emerged that there was a reluctance to remove any data items as a case could be made that all knowledge was relevant, or removal could impact another data item in the set.

Confirmation by comparison can take a number of forms; for instance, comparisons between pre and post system deployment [23], novice and expert results [20] or diagnostic comparisons between expert and system results [14], [27]. Comparison in this research adopted a novice/expert approach. Clinical co-creators (Holders, Reviewers, Gatekeepers) role-played asking the 'new staff' member (the researcher's role – Seeker - in this instance was used as a proxy for the novice) to give them an update on a hypothetical patient's status. Clinical experts identified the relevant data items that would answer the question. The 'new staff' member would review the data set and confirm if the relevant data items were present. The novice/expert assessment yielded approximately 50 additional data items (counted in previous number). The additional data items identified included if a patient referral was sent or the date of their last visit. In addition, four new clinical scores were identified during this process. Clinical experts offered potential explanations for these not being identified earlier. Since the research began, additional knowledge had emerged that would be used in practice but was not captured. For example, there was no reference to COVID-19 signs or symptoms or vaccine status in the data set, yet this would be a frequent (and new) question in practice.

ADR Stage 3 is concerned with reflection and learning. These processes (Reflection and Learning) permeated the entire research process; they were not represented by a separate objective.

VII. ADR STAGE 4: FORMALISATION OF LEARNING

In keeping with an ADR approach described by Sein et al. [3], lessons learned are extracted and formulated into new knowledge once the process is complete. Central to ADR is ongoing group collaboration and reflection (ADR stage 3). These group meetings provided an opportunity to highlight, discuss, and document lessons learned during the process. For this paper, the lessons learned were formalised into this healthcare domain knowledge acquisition method - referred to as the WICKED method. Using the description provided by Purao [76], a method represents a set of "steps, algorithms or guidelines, used to perform a task".

The goal of WICKED is to provide users (working in the healthcare field) with an end-to-end knowledge acquisition method capable of managing DIKW from a variety of sources. See Table II for an overview of WICKED method.

Key learning that emerged included using an initial MND data set, 'Everything' categories and research assessment questions. The following text discusses key learning points.

Initially it was envisioned that the initial MND data set used at the site could not only be adopted as a potential starting point for data collection but also provide a means of comparison once the research was complete. Although both the initial data set and the maximal data set had a similar focus – MND disease, the initial data set was designed as a core or minimum clinical data set. The other, the maximal data set, was intended to

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represent the maximal data set possible. Therefore, while the initial data set provided a starting point, its role as a post-

researcher comparator should be viewed cautiously.

TABLE III
WICKED STEPS, PROCEDURES AND OUTPUTS

Step	Procedures	Outputs
Step 1: Collect	Knowledge seeker role-play as a new staff member Co-creation group review of relevant literature, policies and procedures Co-creation group review of the existing data set	DIKW data corpus reviewed and presented as a set of 'Expert Prompts'.
Step 2: Collate	Phase 1: Form Topic groups or Consideration groups (topic index) Phase 2: Review topic groups to identify an appropriate research assessment question. Phase 3: Identify additional relevant data or information for each research assessment question. Phase 4: Review Topic Groups and Consideration Groups against previously identified categories. These are referred to as 'Everything Categories' and are discussed in this section.	Maximal data set relevant to the knowledge topic.
Step 3: Construct	Co-creation group review and transfer data items from mind maps into a spreadsheet.	Maximal data set constructed (excel document).
Step 4: Confirm	Data set compared to control knowledge base - validation by comparison Data set reviewed by knowledge reviewers - validation by expert consensus.	Confirmed (validated) maximal data set.

The six high-level categories (People/Problems, Systems, Governance/Culture, Clinical Signs and Symptoms, Equipment/Medications and Business Processes) were a useful way to categorise the data collected in this research. We propose that these could have applications in future projects. This research refers to these as 'The Everything Categories'. Future research should explore these categories as potential researcher prompts that could be considered or explored when eliciting knowledge from experts in a healthcare domain.

Feedback from the group indicated that the research assessment questions (Step 2: Collate, phase 2) were useful to focus the data collection (in phase 3) but could benefit from further refinement. For instance, the topic 'All Measures and Scores' adopted the question, "What measures/scores are used in the domain relevant to the knowledge topic?". It was discussed that depending on the individual research aims or knowledge topic, these questions could be designed to be more specific. Using the previous example, a more specific question could be, "What respiratory measures/scores are used in the domain relevant to the knowledge topic?".

Following the review of the lessons learned, the method proposed as having four steps: collect, collate, construct and confirm (see Fig. 1 and Table III). Collate is further distilled into 4 phases (described in Step 2: Collate). Movement across the method is iterative rather than sequential and completes when data saturation occurs. In addition to the key project requirements: knowledge artefact, knowledge topic and key knowledge roles (discussed in ADR Stage 1: Problem Formulation), a control knowledge base acts as a data collection starting point. It is proposed the WICKED method sits within an ADR approach as a supplementary or complementary method.

VIII. EVALUATION OF THE WICKED METHOD

Permission to evaluate the WICKED method at a second healthcare site by an independent researcher (researcher LD) was granted by the clinical lead (the co-creation team linked to this site). A slide deck describing the proposed knowledge acquisition method was developed by the original researcher and submitted as a 'how to' guide that could be used for reference by the second researcher. Further interactions were

limited to ensure the process could be followed and to avoid influencing the second researcher. Similar to the first, the second researcher had a nursing background. The evaluation process was conducted over six months.

Key project requirements were identified by the Seeker (researcher LD) and the domain experts (Holders, Reviewers and Gatekeeper) based at the second site. As there was no existing data set, a patient assessment document (nursing) that was developed previously at the site (over a decade ago) was used. The knowledge topic was "What are the early signs and symptoms of disease progression in multiple sclerosis (MS) patient cohort?". Like the original research, the knowledge artefact was an SRD containing relevant DIKW to the knowledge topic.

Following evaluation, the knowledge artefact contained 1,168 validated data items. This was compared to the control knowledge base (which contained 180 data items), demonstrating an additional 998 items relevant to the knowledge topic. Similar to the initial research, the pre and post comparison is complex, and findings should not be seen as an exact comparison. However, the knowledge artefact was positively evaluated by domain experts (from the study site).

To review the WICKED method, researchers from both studies met to review and discuss their experiences. In total four meetings were held at the end of the research period. Notes were taken during these meetings and the second researcher had an opportunity to review and approve them. These discussions highlighted a number of benefits and limitations of the method.

The benefits discussed included that the method provided a systematic approach to collecting expert KW and guidance on how to collate (collected KW) with data and information from other sources to develop a maximal data set. This was highlighted as 'very useful' to new members of staff who may be unfamiliar with the domain as a means of expediting the learning curve. According to the authors, collecting data using the six 'Everything' categories proved very useful. They noted that topics such as business processes or equipment would not have been topics they traditionally associated with healthcare knowledge. Therefore, having a guide that encouraged investigation of these topics was beneficial.

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The topic 'Equipment' was identified as particularly advantageous by the authors. They noted that this topic yielded many data items. It was discussed that 'equipment' could indicate the types of issues a patient may face, for instance, mobility or communication deficits. In addition, 'equipment' could indicate a change in the patient's clinical presentation that may require new aids or appliances. A further comment was that asking questions role-playing as a new staff member was valuable and prompted the experts (as knowledge holders) to explain in detail to the researcher (as a knowledge seeker).

The main limitation was that the process gave no clear guidance on when to stop data collection (data saturation was used as a heuristic). It also was highlighted that the entire process is labour intensive, relies on the researcher's skills and must be repeated to update the knowledge artefact at a future time. Meaning that in-between updates, the current data set may not represent the most up-to-date knowledge. Another limitation was that it relied on the availability of subject experts.
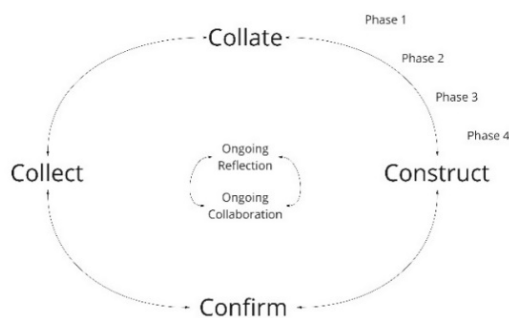

Fig. 1 Overview of the WICKED method

IX. Findings & Discussion

ADR has been applied in many studies [77], [78], but it has not been used to develop a knowledge elicitation method to the authors' knowledge. The first aim of this research was to acquire knowledge from domain experts using an ADR methodology and then collate with other sources of DIKW, including relevant literature and existing data sets into a data corpus. From this data corpus, a maximal data set could be extracted that represented MND knowledge related to early warning signs of disease progression. Once the data items are constructed into the maximal data set, additional confirmation (of the data items) occurs. This data set represented an initial step in developing a knowledge base for an MND patient data platform. While this current research focused on developing the maximal data set, future studies will explore other parts of the larger project.

In addition to developing the maximal data set, a second aim of the research was to extract lessons learned from the development process and formalise them into a researcher-mediated knowledge acquisition method for the healthcare domain – the WICKED method. The title is both an anagram (eliciting and confirming data, information, knowledge, wisdom) and a reference to the concept of wicked problems, which are complex, challenging and have no stopping rule [1], [2]. The WICKED method aims to provide users (working in

the healthcare field) with an end-to-end knowledge elicitation method capable of managing DIKW from various sources using an iterative process. This research resulted in an MND maximal data set containing relevant DIKW represented as data items. The method described is proposed as a supplementary or complementary method to an ADR approach.

The research was directed by the question, "What are the benefits or limitations of a domain-specific knowledge acquisition method?" The final data set contained n = 872 validated data items. Therefore, the WICKED method was deemed to have value as a knowledge elicitation method that merited further exploration.

The method was evaluated at a second healthcare site to gain an independent account of the barriers and limitations. Following this evaluation, the main benefit to emerge was that it provided a systematic approach from collecting to confirming relevant DIKW so that it could be reused beyond the initial exchange. In addition to constructing a maximal data set, incorporating the WICKED method allowed to record the origin of the data items, providing a means to audit the data item's origin.

However, limitations were also evident. Limitations discussed (by the original co-creation group and following evaluation at a second site) relate to the time required to engage with the method, there was no stopping rule, or that the method only acquired DIKW at a point in time. In addition, not everything captured during the process will be relevant to the final knowledge artefact.

Concerning the time required, the research took 12 months and relied on ongoing interaction between the co-creation group and researcher. Healthcare is a busy domain, and this level of commitment may not always be possible for all projects. This limitation was exacerbated by the fact that the method provided no guidance on when to stop collecting data. As new health care knowledge is constantly emerging, it is likely that should the process be repeated, additional knowledge could be captured, or previously captured knowledge made redundant. For instance, as this research was pre-pandemic, no data were captured related to COVID-19. This does not diminish the usefulness of the method. Rather it highlights how healthcare knowledge can evolve. Therefore, the process can only elicit knowledge used (at a study site) during the research period.

Although described as a limitation of the method, the 'no stopping rule' could also be viewed as a characteristic of knowledge in general. DIKW may only be relevant for the duration of the research, mirroring how wicked problems may have no stopping rule [1], [2]. Clinical knowledge is ever-evolving, as evident in the previous Covid example. Providing guidance on an endpoint could be futile, as such a place may not exist. Instead, we propose that knowledge saturation provides a proxy measure that researchers can adopt.

Not all DIKW captured will be relevant to the final knowledge artefact. For example, not all prompts in the Consideration groups could be converted into research assessment questions (or relevant data items). An example was expert advice given (to the knowledge seeker as a new 'researcher') on how notches on a belt buckle could indicate

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weight loss. These pieces of advice (described in the text as 'Considerations'), while useful to the non-specialist, may not generate a data item directly. Furthermore, as they are collected during the process this can add to the time burden of collecting and reviewing. However, in this instance, this prompt did generate a conversation on why weight loss should be included in the data set. Others were less fruitful – such as advice to check a whiteboard to see how many patients were attending the clinic. Group discussions highlighted that these 'considerations' could represent expert knowledge or wisdom. Therefore, if they did not generate a data item or point to one, they could be useful for future projects; a record of these was maintained.

Both researchers (main research and evaluation at the second site) had clinical experience (nursing). Their experience, however, was not related to the specialties at either study site. Both researchers spent time with the relevant clinical experts discussing the site to prepare for the research. As a precaution, without future research, we cannot reach a conclusion as to the utility (of the WICKED method) to a non-clinical researcher.

Reviewing the results considering the three common challenges noted (from the literature review), accessing expert knowledge was not an issue. Experts were identified through their engagement in the project (clinical co-creation group) and established clinical reputations. The group had also widely published on the topic of MND. This engagement also removed any access issues. Role-playing as a new staff member allowed tacit aspects of knowledge to be converted to explicit (and codified), and trust was built due to the reputations of experts.

Regarding confirming the quality of knowledge captured, as the MND-MDT was considered experts in their field this helped build trust in the quality of the knowledge captured. Confirmation of quality was an ongoing process throughout the research, encompassing both opportune (during group meetings) and planned (by comparison to control knowledge base and expert consensus). In both researches (initial and evaluation), the comparison between the initial data set used and maximal data set should be viewed with caution. Both the pre and post data sets were developed for different usage. For instance (in the main research) the initial data set was a core clinical data set developed to populate an MND registry. Whereas the maximal data set was intended to capture additional data items including and beyond core clinical data, for instance, the social and economic implications of MND. Therefore, it is proposed that the main value of using an initial data set is in its use as a starting point for knowledge elicitation.

In addition to the time required, a challenge not addressed was the continual capture of knowledge. As the DIKW that underpinned the data set was only relevant to the length of the research (12 months), the process will need to be repeated to add and remove redundant data items. This will have time (and possibly financial implications) for the study site.

While it is difficult to state with certainty that this is the absolute total DIKW available at the study site, adopting the proposed method did result in a maximal data set (or at least a larger data set) that was managed in a systematic and auditable way. In addition, it demonstrated utility in managing large volumes of DIKW from various sources and transferring these into data items, while also providing guidance on categories to explore as part of the acquisition process. Future work on the method will address these limitations, mindful of maintaining its strengths.

X. Conclusions

The two outputs from this research were a maximal data set that incorporated DIKW from various sources, including specialist clinical knowledge and a knowledge elicitation method – the WICKED method. This research represents a first step in developing an MND patient data platform. The method was positively evaluated at a second healthcare site. The main benefits noted were that the method was systematic, auditable, and provided guidance on the knowledge acquisition process. The main limitations were that it was time consuming, had no stopping rule and only acquired DIKW during the period of the research. Furthermore, we acknowledge that the method was only evaluated using researchers with clinical experience. Future work will address these limitations.

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