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Research Paper

'Knowledge exchange' workshops to optimise development of a risk prediction tool to assist conveyance decisions for suspected seizures – Part of the Risk of ADverse Outcomes after a Suspected Seizure (RADOSS) project

Adam J. Noble [a,*], Beth Morris [a], Laura J Bonnett [b], Markus Reuber [c], Suzanne Mason [d], Jasmine Wright [e], Richard Pilbery [f], Fiona Bell [f], Tom Shillito [g], Anthony G. Marson [h], Jon M. Dickson [i]

[a] Department of Public Health, Policy and Systems, Institute of Population Health, University of Liverpool, Liverpool, UK
[b] Department of Health Data Science, Institute of Population Health, University of Liverpool, Liverpool, UK
[c] Department of Neuroscience, School of Medicine and Population Health, University of Sheffield, Sheffield, UK
[d] Sheffield Centre for Health and Related Research, School of Medicine and Population Health, University of Sheffield, Sheffield, UK
[e] Public contributor, UK
[f] Yorkshire Ambulance Service NHS Trust, Wakefield, UK
[g] Epilepsy Action, Leeds, UK
[h] Department of Pharmacology and Therapeutics, Institute of Systems, Molecular and Integrative Biology, University of Liverpool, Liverpool, UK
[i] Population Health, School of Medicine and Population Health, The University of Sheffield, Sheffield, UK

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ABSTRACT

Purpose: Suspected seizures present challenges for ambulance services, with paramedics reporting uncertainty over whether or not to convey individuals to emergency departments. The Risk of ADverse Outcomes after a Suspected Seizure (RADOSS) project aims to address this by developing a risk assessment tool utilizing structured patient care record and dispatch data. It proposes a tool that would provide estimates of an individual's likelihood of death and/or recontact with emergency care within 3 days if conveyed compared to not conveyed, and the likelihood of an 'avoidable attendance' occurring if conveyed. Knowledge Exchange workshops engaged stakeholders to resolve key design uncertainties before model derivation.

Method: Six workshops involved 26 service users and their significant others (epilepsy or nonepileptic attack disorder), and 25 urgent and emergency care clinicians from different English ambulance regions. Utilizing Nominal Group Techniques, participants shared views of the proposed tool, benefits and concerns, suggested predictors, critiqued outcome measures, and expressed functionality preferences. Data were analysed using Hamilton's Rapid Analysis.

Results: Stakeholders supported tool development, proposing 10 structured variables for predictive testing. Emphasis was placed on the tool supporting, not dictating, care decisions. Participants highlighted some reasons why RADOSS might struggle to derive a predictive model based on structured data alone and suggested some non-structured variables for future testing. Feedback on prediction timeframes for service recontact was received, along with advice on amending the 'avoidable attendance' definition to prevent the tool's predictions being undermined by potential overuse of certain investigations in hospital.

Conclusion: Collaborative stakeholder engagement provided crucial insights that can guide RADOSS to develop a user-aligned, optimized tool.

* Corresponding author at: Department of Public Health, Policy and Systems, Institute of Population Health, Whelan Building, University of Liverpool, UK L69 3GL.
E-mail address: adam.noble@liverpool.ac.uk (A.J. Noble).

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1. Introduction

Suspected seizures are a common presentation to English ambulance services,[1–3] and paramedics say it can be challenging to decide which patients presenting with a suspected seizure should be conveyed to hospital.[4–7] RADOSS [8] aims to address this knowledge gap by developing a risk prediction tool to assist paramedics. In this paper, we report on findings from a series of Knowledge Exchange (KE) workshops attended by stakeholders to optimize tool development.

While suspected seizures can be dramatic and life-threatening, most cases attended by the ambulance service are uncomplicated manifestations of established conditions, mainly epilepsy and non-epileptic attack disorder (NEAD).[1,2,9] Conditions such as syncope, alcohol withdrawal, head injury, and hypoglycaemia account for the remaining minority of suspected seizure incidents.[2].

Despite the typically uncomplicated nature of suspected seizure incidents,[3] ~ 70 % are conveyed to emergency departments (EDs) [1,2,9] and can result in 'avoidable attendances'. Avoidable attendances, as defined by England's National Health Service using O'Keeffe et al.'s criteria [10] (Table 1), are undesirable as they can increase demand on ambulance services, contribute to overcrowding in EDs, cause patient harm and are costly. [11 12,13 14].

Decisions whether to convey a patient to hospital can be influenced by factors beyond clinical need.[15,16] Some paramedics say they struggle to identify cases suitable for non-conveyance and want help in identifying the risks and benefits of conveying and not conveying individuals.[4–7] RADOSS seeks to address this by developing a risk prediction tool. Such tools use ≥ 2 pieces of patient data to generate a personalised estimate of the likelihood that an individual will experience certain endpoints within a.

specified time frame.

RADOSS proposes the new tool provides estimates of two outcomes known to feature in paramedics' decision making [17] – namely, likelihood of death and/or recontact with the urgent and emergency care system (within 3 days), as well as the likelihood of an attendance meeting the definition of an avoidable attendance if conveyed. The tool could be deployed when paramedics manage cases that do not present an obvious need for conveyance to ED.[3] Such tools show benefit in analogous situations. Moreover, paramedics use them for other presentations [3] and have expressed a desire for more tools like this to aid decision making.[18].

To support the development of robust risk prediction tools and facilitate use, statistical standards are available.[19] However, health innovations may not be adopted if user and recipient need, preference and workflow are not considered.[19] With this in mind, four aspects needed exploration with stakeholders.

The first was perceived need. Both service users and clinicians have articulated the necessity for change (see[20]). Nevertheless, their perspectives regarding the potential of a risk prediction tool to meet this need, along with any associated concerns and expectations, remained unexplored.

The second was which items to test for inclusion in the tool, here referred to as 'candidate predictors'. Whilst 'on-scene', paramedics lack access to a patient's full medical record. What is available is the information they record within structured fields on the patient's care record (PCR) and what was recorded by call handlers in computer aided dispatch (CAD) systems. Lots of this information could potentially predict outcomes. However, there are statistical limits on how many variables RADOSS can test.[21] Insights from individuals with lived and clinical experiences, including expected strength of association with the outcomes, reliability, and accessibility during conveyance decision-making, could inform RADOSS' selection for testing and subsequent prioritization.

The third area pertained to outcome measures. It was necessary to understand whether RADOSS' definitions of them were considered suitable by clinicians to guide their decisions.

Finally, it was necessary to start to understand clinicians' preferences for tool functionality and implementation. This exploration is particularly significant as clinicians' preferences could influence model derivation, including considerations like limits on variables clinicians are willing to input.

To address these knowledge gaps, KE was completed with urgent and emergency care clinicians (comprising of ambulance service paramedics and ED clinicians), service users, and their significant others.

2. Methods

2.1. Design

Six KE workshops were conducted. Their design, led by Wilkins and Cooper's [22] KE definition, focused on a two-way exchange between researchers and research users. To secure comprehensive insights [23] and facilitate recruitment, an online group format was chosen. Reporting conforms with the Standards for Reporting Qualitative Research. [24].

2.2. Participants

Purposive and diverse samples of 20–30 service users and 20–30 clinicians were sought.

Service users needed to be aged ≥ 18 years and self-report having had contact with the ambulance service during the prior 12 months for a suspected seizure or be a significant other to a person who had (Table 2). They were identified by three patient groups affiliated with the target population circulating recruitment advertisements in March 2023: 'FND Hope' shared the study advert twice on their public social media platforms; 'Epilepsy Action', as well posting on social media twice, advertised the study on their volunteering and study opportunities webpages (see Acknowledgements); and finally, 'Speak up Advocacy' (Sheffield), a group run by and for people with learning disabilities and autistic people, sent the study advert to its members. All persons interested in participating conducted our study team by email or phone. The team confirmed individuals' self-reported eligibility, sent them a Participant Information Sheet, answered any questions they had and secured written, informed consent. No medical records were accessed to confirm a person's eligibility to participate, nor their diagnosis/es.

Table 1
Definition of an 'avoidable attendance'[a].

A person has been involved in an avoidable attendance if routine hospital coding for the attendance indicates it:	
• ***did not result in the person being investigated***	*Except* [b]: urinalysis; dementia test; pregnancy test; dental investigation; glucose measurement; peak flow; visual acuity testing
• ***did not result in the person being treated***	*Except* [b]: new prescription, medication review, social assessment, psychosocial assessment, recording vital signs, dental treatment, activities of daily living assessment, mobility assessment, closure of a skin wound by tape, gluing of wound, application of a minor dressing; guidance/advice).
• ***AND the person was discharged***	*Be it to*: home; residential care; custody.

Notes: [a] O'Keeffe et al.'s [10]definition has been iteratively refined. Presented here is an abbreviated version of a recent iteration[44];
[b] Exceptions are those investigations/ treatment that a multidisciplinary expert group judged could plausibly have been provided in a non-emergency care setting, rather than requiring attending at a Type 1 emergency department.

Table 2
Inclusion and exclusion criteria for participant Knowledge Exchange workshops and rationale.

GROUP	INCLUSION CRITERIA	EXCLUSION CRITERIA	NOTES ON RATIONALE
Service users	▪ Aged ≥ 18 years (no upper age limit); Attended to by an ambulance during prior 12 months for a suspected seizure/s OR A significant other to such a person (e.g., family member, friend) who was aged ≥ 16 years; Incident could be related to a self-reported diagnosis of either epilepsy and/or NEAD. Able to provide informed consent and participate in a workshop independently in English; Lives in England.	▪ Severe current psychiatric disorders (e.g., acute psychosis); Terminal medical condition.	▪ Project protocol stated intention to recruit persons who had been attended to be an ambulance aged ≥ 16 years. This was to align with national ambulance guidelines [3] which note conveyance is only always required for those aged < 16 years. Ethical approval, however, required persons taking part because they had been attended to by an ambulance needed to be aged ≥ 18. Significant others were recruited since they can be present when ambulances attend, and it is to them that patients can delegate care decisions.[45] Epilepsy and NEAD account for ~ 70 % of suspected seizure ambulance incidents.[2]
Clinicians	▪ Aged ≥ 18 years (no upper limit); Paramedic, ED doctor or nurse; Works in England; Able to provide informed consent and participate in a workshop independently in English.		▪ Paramedics were recruited since it is their decision making the tool seeks to support. ED clinicians were principally recruited because their expertise in how seizures are managed in ED meant they could help identify challenges of using the avoidable attendance definition for them;

Notes: ED, emergency department; NEAD, non-epileptic attack disorder.

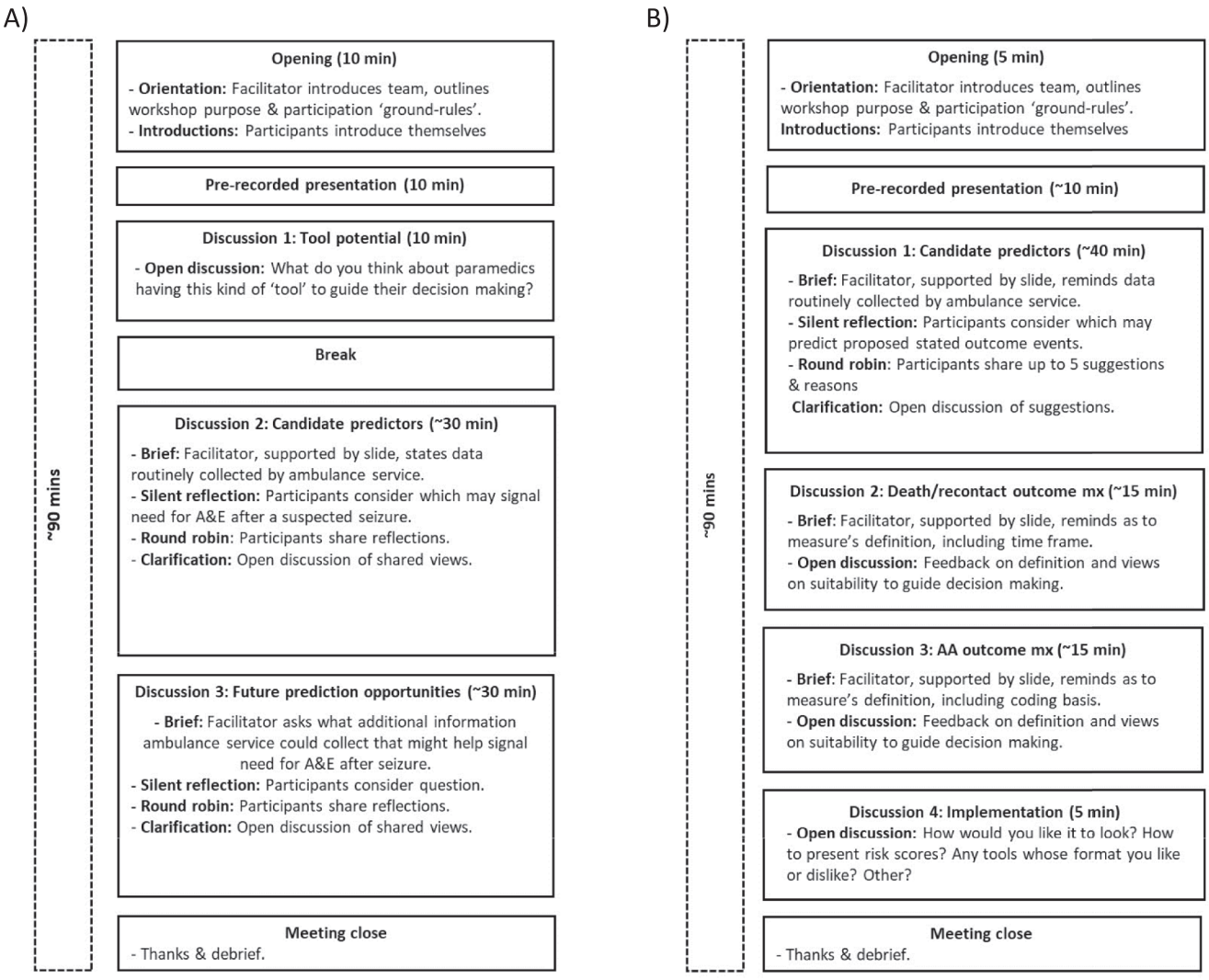

Fig. 1. Structure of (A) service user and (B) clinician workshops. *Notes:* A&E, Accident and Emergency department; min/s, minute/s.

Eligible urgent and emergency care clinicians, comprised of ambulance service paramedics, or ED doctors and nurses (Table 2). To aid recruitment, England's 10 regional ambulance services and the Royal College of Emergency Medicine Yorkshire and Humber board were asked to circulate an advertisement. Adverts were also placed within Facebook interest groups (Acknowledgements).

2.2.1. Ethics

The Health Research Authority (23/HRA/1439) and University of Liverpool Ethics Committee approved the study (11450). Participants were offered a £10 voucher.

2.3. Procedure

Workshops for service users and clinicians ran separately. All were facilitated by BM, a qualitative health services researcher. LJB was present at clinician workshops to assist with statistical questions. AN was at service user workshops to offer support.

Topic guides were developed on the basis of the literature [25] and uncertainties regarding the tool's future implementation,[26] and were piloted with 8 service users (Supplementary File 1). Nominal Group Techniques[27] were used to facilitate open and constructive sharing and discussion of views.

Fig. 1 shows workshop structure. They started with a presentation to orientate participants to the proposed tool (Supplementary File 2).

To gather predictor suggestions, service users and clinicians were presented with a slide displaying the information routinely recorded within structured data-fields and accessible to paramedics whilst 'on scene'. Service users were asked which might indicate care needs following a seizure; clinicians were asked which might predict the likelihood of the outcomes. They could make suggestions for the outcomes separately or collectively. Groups were also asked to provide suggestions not included on the slide. All service user responses were recorded 'live' on screen by AN within a table (Supplementary File 1).

With participants' consent, workshops were audio-recorded and transcribed. Participants did not review transcripts.

2.4. Analysis

2.4.1. Candidate predictors

The objective was to generate a list of candidate predictors prioritised by service users and a list for clinicians. Thus, for service users BM extracted the tables generated by their workshops and merged them. For the clinician list, BM reviewed transcripts, extracting candidate suggestions. All suggestions were classified according to whether they are captured within structured ambulance electronic PCR/ CAD data-fields (Table 3 footnotes gives further detail).

2.4.2. Perceived need, candidate justification and views on functionality/ implementation

Qualitative findings on these topics needed to be analysed with high methodological rigour but swiftly enough to inform model derivation. Thus, we employed Hamilton's Rapid Analysis method.[28] Instead of line-by-line coding, analysts review transcripts, populating a 'summary template' for each data collection episode with relevant data segments, creating 'episode profiles'.

For RADOSS, Rapid Analysis involved BM and AN independently populating a summary template for each workshop and then holding consensus meetings to consolidate their work and create a final, populated template for each. Templates were generated a priori (Supplementary File 3) and included domain headings based on the topic guide.

Matrices helped to support the identification of similarities, differences and trends across workshops and informants.[29] Aggregated results were presented to the wider team to facilitate cross-checking before finalisation and decisions being taken about their implications for the project.

Illustrative quotations from participants (P) are provided, with Supplementary File 4 providing additional ones. There has been minor editing of some to preserve anonymity and ensure clarity.

3. Results

3.1. Participants

From 47 eligible service users responding to the advert, 33 were available for, and booked in to attend a workshop. A total of 26 ultimately participated (17 females, 9 males; aged 18 to 85). They included, 18 people with diagnosed seizure disorders and 8 significant others. Service users came from 7 of England's 10 ambulance regions. Fig. 2 shows the recruitment process, workshop details and composition of the groups.

From 60 clinicians contacting us, 32 were available for, and booked in to attend a workshop. A total of 25 ultimately participated (15 females, 10 males). They included 19 paramedics (from 6 ambulance regions) and 5 ED consultant doctors and 1 ED doctor in training (from 6 EDs).

Service user workshops occurred in April 2023, lasting 74 to 132 min, while clinician workshops occurred in June 2023, lasting 82 to 91 min.

3.2. Perceived need

3.2.1. Anticipated benefits

Service user and clinician participants supported the proposed tool's development. Clinicians were keen for additional support for what they identified as complex decisions:

> "We have to make decisions based on a patient presentation who has been with us for 30 min… in ED …they get…longer…It can be difficult." (P31; Male, paramedic)

Service users shared instances of important care interventions by the ambulance service. Most though, said their prevailing experience was transport to ED when they believed it was not required. They felt the tool might mitigate against knowledge gaps they perceived some paramedics to have which contributed to this:

> " *I agree I think it's a good thing…The number of paramedics that have pulled a phone out and 'Googled' what is NEAD…is frankly alarming…some…have been a bit shaky with epilepsy as well."* (P7; Female, person with epilepsy and NEAD)

Service users emphasised ED visits when not required were not 'risk-free'. Indeed, some said there was a need to "de-medicalise" uncomplicated seizures:

> *"Need to recognise that going to ED when not necessary can be stressful which itself can elicit further seizures. When I wake up and find myself in ED it can be really distressing…"* (P21; Male, person with epilepsy)

3.2.2. Potential concerns

Service users and clinicians did not want risk estimate/s from the proposed tool to *dictate* care choices. Rather, they wanted them to be one, albeit important, piece of information accounted for. Service users wanted their preferences to be heeded:

> *"the experience of the persons experiencing the seizures and the carers should not be dismissed… if paramedics had more experience than me, I would fall off my chair…"* (P5; Female, significant other to person with epilepsy and NEAD).

Most clinicians said paramedics needed to still be permitted to use their judgement since there may be additional factors of importance:

Table 3
Candidate predictors suggested by workshop participants and their reasons.

Available from structured data fields [a]			Not available from structured data fields		
Variable	**CLINICIANS**	**SERVICE USERS**	**Variable**	**CLINICIANS**	**SERVICE USERS**
	Suggested? *If so, reasons*	**Suggested?** *If so, reasons*		**Suggested? If so, reasons**	**Suggested? If Y, reasons**
Time of day	***Yes*** *"…time of day is really important because there's… a lack of anyone around in the middle of the night, you know, be that family members, friends, somebody who kind of corroborate history…" (P37, Female, paramedic)*	***No***–	***Known seizure diagnosis?***	***Yes*** *"First seizure would obviously always come into hospital [for full assessment]…"(P27, Male, ED clinician)*	***Yes*** *"What is that individual's normal? ….somebody having a full, first time tonic clonic… that's a different matter isn't it…" (P9, Female, significant other to person with epilepsy)*
Who made call	***Yes*** *"…I spend time in 'comms'… you can listen in to phone calls… a lot of jobs that go down the seizure code, I would say are probably not seizures." (P46, Female, paramedic)*	***Yes*** *"We've… had police involved because someone's mistaken my son's behaviour as being drunk" (P9, Female, significant other to person with epilepsy)* *"If I'm at home it's fine…but it stops you from being safe to go out…because the public don't understand seizures." (P22, Female, person with epilepsy)*	***If diagnosed, 'normality' of presentation***	***Yes*** *"…if…things are not normal…I'd be more comfortable with them having a… thorough assessment [at ED]." (P28, Male, paramedic)* *"the main things to me…is normal versus abnormal, be that pre seizure, during and post…" (P39, Female, paramedic).)*	***Yes*** *"…its crucial for the ambulance service to know whether this is a typical or non-typical seizure for that person…" (P23, Female, person with NEAD)*
Location	***Yes*** *"[sometimes]… the only reason they came in was because they had the 'audacity' of having a seizure in [shop]." (P27, Male, ED clinician)*	***Yes*** *"Its always a problem when its in a public place… We as a family feel outside pressures… I'm sure the paramedics do. That they should be…doing something … people don't want somebody having a seizure where they are… (P9, Female, significant other to person with epilepsy))* *"where it is happening is important…whether the environment is safe…" (P14, Female, person with epilepsy and NEAD)*	***Type of seizure***	***Yes*** *"whether they have clusters or not… when they do…that might make that patient more unsafe." (P27, Male, ED clinician)*	***Yes*** *"So I get jamais vu…you don't know where you are… people just think they are dealing with someone who is drunk or on drugs…whereas if you are on the floor having a fit it is much more obvious… "(P22, Female, person with epilepsy)*
Vital signs	***Yes*** *"most important are physiological variables and… observations… blood pressure, GCS, pulse…" (P51, Male, paramedic)* *"Any abnormal vital signs… after a seizure you might have a bit of a tachycardia… rest should…soon return to normal… if there were things … that would be a red flag…."(P41, Female, ED clinician)*	***Yes*** *"In my daughter's case …for an epileptic seizure there will be some form of respiratory distress… [for her] non-epileptic seizures that doesn't happen. This can be important to distinguish her care needs" (P5, Female, significant other to person with epilepsy and NEAD)*	***Type of seizure disorder***	***Yes*** *"…the actual physiology behind what's made them seize…I'd be potentially less worried about psychogenic seizures versus an epileptic seizure from a brain injury perspective" (P40, Male, paramedic)*	***Yes*** *"…distinguish between whether a seizure is epileptic or non-epileptic. That will give them a… massive clue…" (P5, Female, significant other to person with epilepsy and NEAD)*
Injury presence	***Yes*** *"…a minor head injury in a postictal patient…the presence or absence… increases person's requirements for assessment or their likelihood of recontacting…" (P47, Male, paramedic)* *"Presence of injuries makes a attendance more likely to happen." (P41, Female, ED clinician)*	***No*** -	***Comorbidities*** [b]	***Yes*** *"Anybody who has a secondary seizure, so say…due to brain metastases… you should convey them." (P33, Female, ED clinician)*	***Yes*** *"Be very aware of overlapping conditions, like PTSD, that can impact need and desire to go to ED…" (P7, Female, person with epilepsy and NEAD)*
Neurological deficit	***Yes*** *"…if there's a seizure with kind of ongoing focal neurology… that would be one that's… clearly risk of necessitating… conveyance to hospital." (P34, Female, ED clinician)*	***No*** -	***Potential triggers***	***Yes*** *"…is there any indication of illness…diarrhoea and they're not absorbing their meds… something… which you would then want to investigate further." (P42, Female, ED clinician)*	***Yes*** *"What are you doing before it's happening?… understanding that if that happens again that the likelihood of me having a seizure again is very high. So maybe moving yourself out of that situation…" (P14, Female, person with epilepsy and NEAD)*

(*continued on next page*)

Table 3 (*continued*)

Available from structured data fields [a]			Not available from structured data fields		
Variable	**CLINICIANS**	**SERVICE USERS**	**Variable**	**CLINICIANS**	**SERVICE USERS**
	Suggested? *If so, reasons*	**Suggested?** *If so, reasons*		**Suggested? If so, reasons**	**Suggested? If Y, reasons**
Pregnancy/Alcohol/non-prescribed drugs	***Yes*** *"important to think about drugs and alcohol... [illegible] alcohol related seizure, either withdrawal or just actually alcohol related" (P27, Male, ED clinician)* [illegible] *(P33, Female, ED clinician)*	***No*** -	***Competent carer/User preference (presence)***	***Yes*** *"...[illegible]" (P27, Male, ED clinician)* [illegible] *(P36, Female, paramedic)* [illegible] *do?" (P28, Male, paramedic)*	***Yes*** *"Paramedics need to actually listen... [illegible] oh, she [illegible] (P15, Female, person with epilepsy and NEAD) consideration needs to be taken with regards what people are saying..." (P14, Female, person with epilepsy and NEAD)*
Treatments given	***Yes*** *"...what type of treatment was given by the ambulance crew.. diazepam or was the seizure self limiting... that would probably change...the risk a little bit.." (P43, Male, paramedic)* *"...if you're giving repeat doses...like it might indicate there's more risk for that patient." (P49, Female, paramedic)*	***No*** -	***Witness***	***Yes*** *"...if nothing's been witnessed and they just sort of woke up on the floor, that complicates the picture a little bit." (P29, Female, paramedic)* *"...if there is a clear history given by bystanders that essentially is a reflective of the typical seizure pattern versus no available history, then I suppose that would be your predictor to ...necessitating conveyance to hospital." (P33, Female, ED clinician)*	***Yes*** *"...usually paramedics will just say 'right that is you off to A&E', whereas if you are with someone who has seen the seizure who can say right that is normal case, he can sleep it off...in my home environment..." (P21, Male, person with epilepsy)*
Learning disability	***No*** -	***Yes*** *-"My son has a significant learning disability...his most recent seizure was when he was out alone... it was his first tonic for 5 years... he was saying 'please don't take me to hospital, I am fine... that wasn't right.. he had sustained quite a serious head injury...If they had relied on the patient...we would have been scared stiff..." (P9, Female, significant other to person with epilepsy)*	***Staff experience***	***Yes*** *"...a lot of people are taken to hospital still because it's the easy thing to do. ...maybe older staff you know 'you're never gonna get in trouble for taking the patient to hospital'... that should probably be taken into consideration." (P28, Male, paramedic)*	***Yes*** *"The traditional medical model is ..., I'm the paramedic – I tell you what to do', you will find that with the older ones. The younger ones tend to be like 'we're going to help you take responsibility for it' which actually is more empowering." (P14, Female, person with epilepsy and NEAD).*
			Care plan [c]	***Yes*** *"anybody who's got a care plan could be less likely to be... conveyed...." (P33, Female, ED clinician)* *"The individual care plan...there can be...a red, amber, green section...What's normal for me? What's not normal for me?" (P32, Female, paramedic)*	***No*** -
			Alternative care pathway provision	***Yes*** *"...available options, like alternative care pathways. Might depend on...time of day ..." (P37, Female, paramedic)* *"...if you're not going to convey them, you need to just think about how you can feed them into other services..." (P33, Female, ED clinician)*	***No*** -
			Previous ambulance contacts [d]	***Yes*** *"...looking if they've had any previous admissions for this kind of thing." (P32, Female, paramedic)*	***No*** -
			Previous HDU/ ICU contact	***Yes*** *"...be interested if they had any previous ICU and our HDU admissions due to seizures and therefore got potential to escalate from a normal self resolving [seizure]." (P39, Female, paramedic)*	***No*** **-**
			Relationship with ambulatory services	***Yes*** *"...the quality of their relationship... with their healthcare*	***No*** -

(*continued on next page*)

Table 3 (*continued*)

Available from structured data fields [a]			Not available from structured data fields		
Variable	**CLINICIANS**	**SERVICE USERS**	**Variable**	**CLINICIANS**	**SERVICE USERS**
	Suggested? *If so, reasons*	**Suggested?** *If so, reasons*		**Suggested? If so, reasons**	**Suggested? If Y, reasons**
				providers…some know that the neuro team really well, they know… why they're potentially had a fit… versus this group of patients who just you know are not connected…"(P44, Male, paramedic)	
			Other prescribed medications	***Yes*** *"…medications they are on that aren't for epilepsy, say so like anticoagulants etcetera, because obviously that would probably change… whether I need to go to ED or whether urgent care and stuff would be appropriate." (P38, Female, paramedic).*	***No*** -

Notes: A&E, accident and emergency department; comms, communications; ED, emergency department; GCS, Glasgow Coma Scale score; HDU, high dependency unit; ICU, intensive care unit; NEAD, non-epileptic attack disorder; neuro, neurology; P, participant; PTSD, posttraumatic stress disorder.
We note that some of the variables might not be directly recorded within a structured data field but may be discernible from data recorded within one or more other structured fields (e.g., service user having a learning disability might be indicated by the CAD fields, 'Where call has originated from' and 'Pickup Location Type' or the PCR field 'Incident Location Type'). In such instances, we have classified these variables as being available from a structured data field and accessible for derivation.

[a] The grouping of the candidate predictors according to whether or not they are recorded within structured data fields was supported by a data-dictionary, generated by the Yorkshire Ambulance Service (YAS). It indicates the data its staff record within structured Patient Care Record (PCR) or computer aided dispatch (CAD) data fields for incidents and which will be accessible for the purposes of derivation via the 'CURED+' data set. CURED + will be used by RADOSS to derive and validate the prediction model. Further details on CURED + are available via RADOSS' protocol.[20] In brief, CURED + is being developed by the University of Sheffield's Centre for Urgent and Emergency Care Research. It maps urgent and emergency care use by individuals served by the YAS from 2011 to 2022 and will contain records of all ambulance contacts which will be linkable to any subsequent ambulance, hospital (ED, inpatient) and death records.

[b] Information on comorbidities is potentially available via different sources. However, it is not routinely available for all patients, nor recorded for all.

[c] Within England, guidelines state all adults with epilepsy should have an agreed and comprehensive written epilepsy care plan.[46] One section it should include is information on "first aid, safety and injury prevention at home and at college or work".[47] Care plans – or pertinent information derived from them –are not routinely accessible to urgent and emergency care staff for people with seizure disorders.

[d] This is potentially derivable for all, but it is usually only available for select patients, such as 'frequent callers', those with calls within the last 24 h.

> *"You still need to be allowed to use judgement…the tool assumes there is a safe alternative for those who on paper don't need to have come to ED…it isn't always available or possible…"* (P41; Female, ED clinician)

3.3. Candidate predictors

3.3.1. Variables routinely available to paramedics at the time and recorded within structured fields

Stakeholders together suggested ten variables or variable 'families' which might be predictive of the likelihood of death/ recontact and occurrence of an avoidable attendance (Fig. 3). These included, but were not limited to, vital signs, presence of a learning disability, incident time, location, who made the call and treatments provided. There was partial overlap in clinician and service user suggestions. Table 3 shows the reasons participants offered for their potential importance.

In certain instances, the variable was suggested to indicate a need for additional investigation or treatment in ED (e.g., significant injury, neurological deficit). In other cases, it complicated paramedics' understanding of the person's needs (e.g., caller identity) or limited their ability to provide care beyond ED (e.g., time of day). Although clinicians were encouraged to propose predictors for the two outcomes separately, most did not.

3.3.2. Variables not routinely available to paramedics at the time and/or not recorded within structured fields

Participants suggested 16 variables not currently captured within structured PCR data fields that might also be predictive (Fig. 3). They included seizure type, presence of a witness, availability of alternative care options and the attending paramedic's experience. Table 3 shows stakeholders' reasons.

Clinicians mentioned that paramedics could record information on some of the variables in PCR free-text sections. The implications of RADOSS not accessing this information were debated. Some considered it a limitation, while others saw it as less significant. The latter argued that it does not reflect what is available to paramedics during conveyance decisions.

> "*…think how paramedics fill in the PCR…demographic information gets 'pulled' straight away… next thing is…the observations and…primary survey…. These might not be the most useful variables, but they're the ones filled in…when…deciding whether to take them to hospital… If you are getting to the stage where you're writing your free text up… you're already in the 'headspace' of your…conveyance decision"* (P51; Male, paramedic)

3.3.3. Matters complicating deriving a predictive tool

Clinicians and service users identified things they said might make it challenging to derive a model able to make precise predictions.

The first was some patients may be given inappropriate care. Thus, the information recorded on the PCR about the incident may not reflect patient need. The example participants gave was medication being inappropriately given to people with NEAD:

> *"….with the FND [functional neurological disorder] seizures I've been given diazepam a few times…that just makes it worse…"* (P15; Female, person with epilepsy and NEAD)

Another reason the PCR might not reflect patient need was measures used by the ambulance service might not be sufficiently sensitive to differentiate between presentation severity:

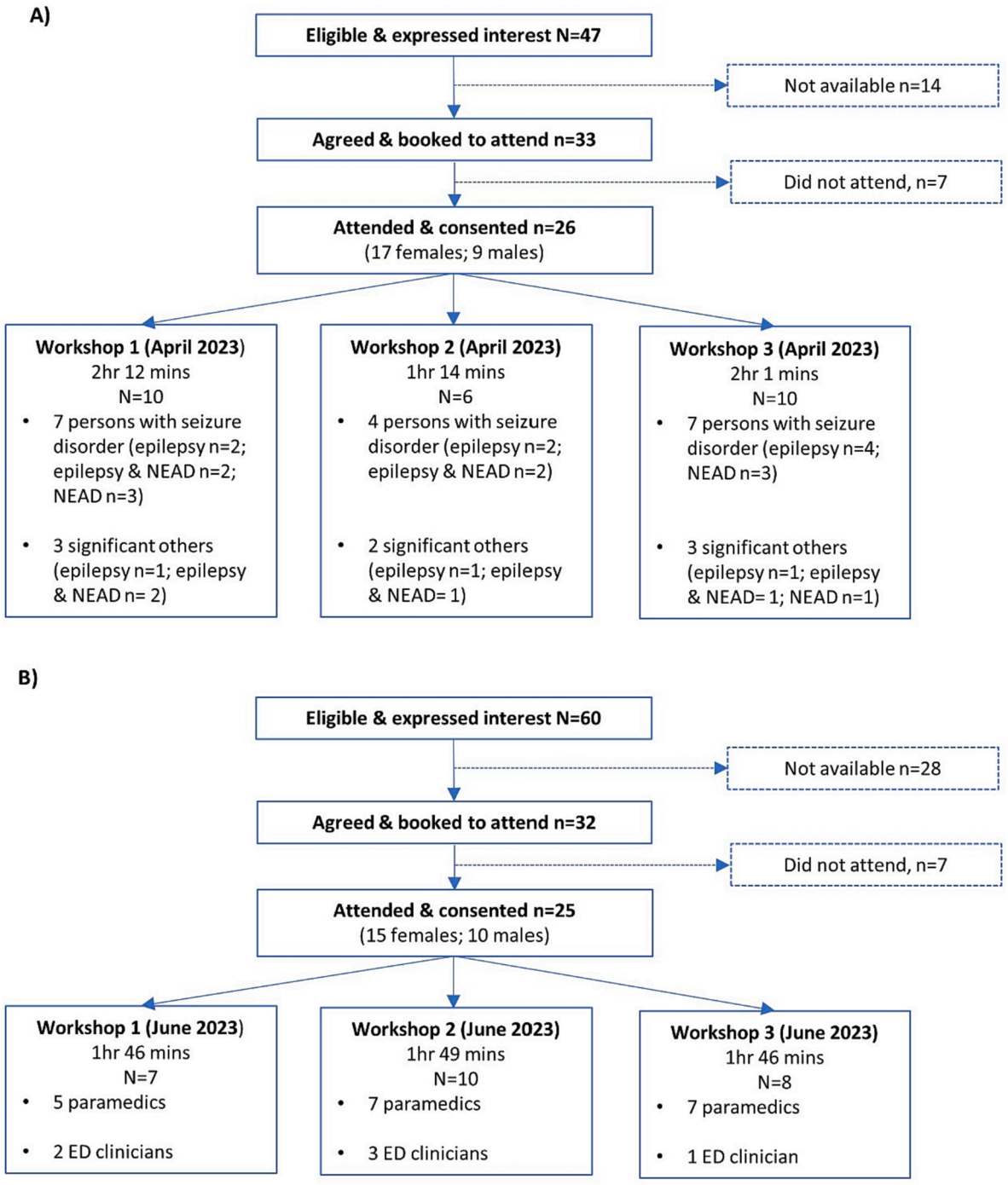

Fig. 2. Recruitment flow diagram for, and composition of, workshops for (A) service users and (B) clinicians.

"….[measures like the] Glasgow Coma Scale are not always the best tools…someone who's post-ictal could have a GCS hovering around 13,14… for say 20 min. During that 20 min you are…seeing them becoming less postictal, but the GCS is still hovering at 14." (P44; Male, paramedic).

A third challenge was potential inaccuracy of some information recorded within structured PCR/CAD fields. Inaccuracies could arise from information offered by bystanders and patients themselves:

"…people misinterpret, misunderstand, particularly observers…I've asked people at work [witnessing the same seizure] to describe it… You wouldn't believe the variation you get in stories……" (P22; Female, person with epilepsy)

"…I'll often be saying something in the post-ictal phase, but it's not what I think I've said." (P24; Male, person with epilepsy)

A final issue participants said might complicate matters was that certain presentation features have different implications for care needs, depending on the person's seizure disorder. An example provided by participants was the meaning of seizure activity:

"…With dissociative seizures I've had a seizure for 45 min…if that was epilepsy you would go straight to hospital whereas you wouldn't

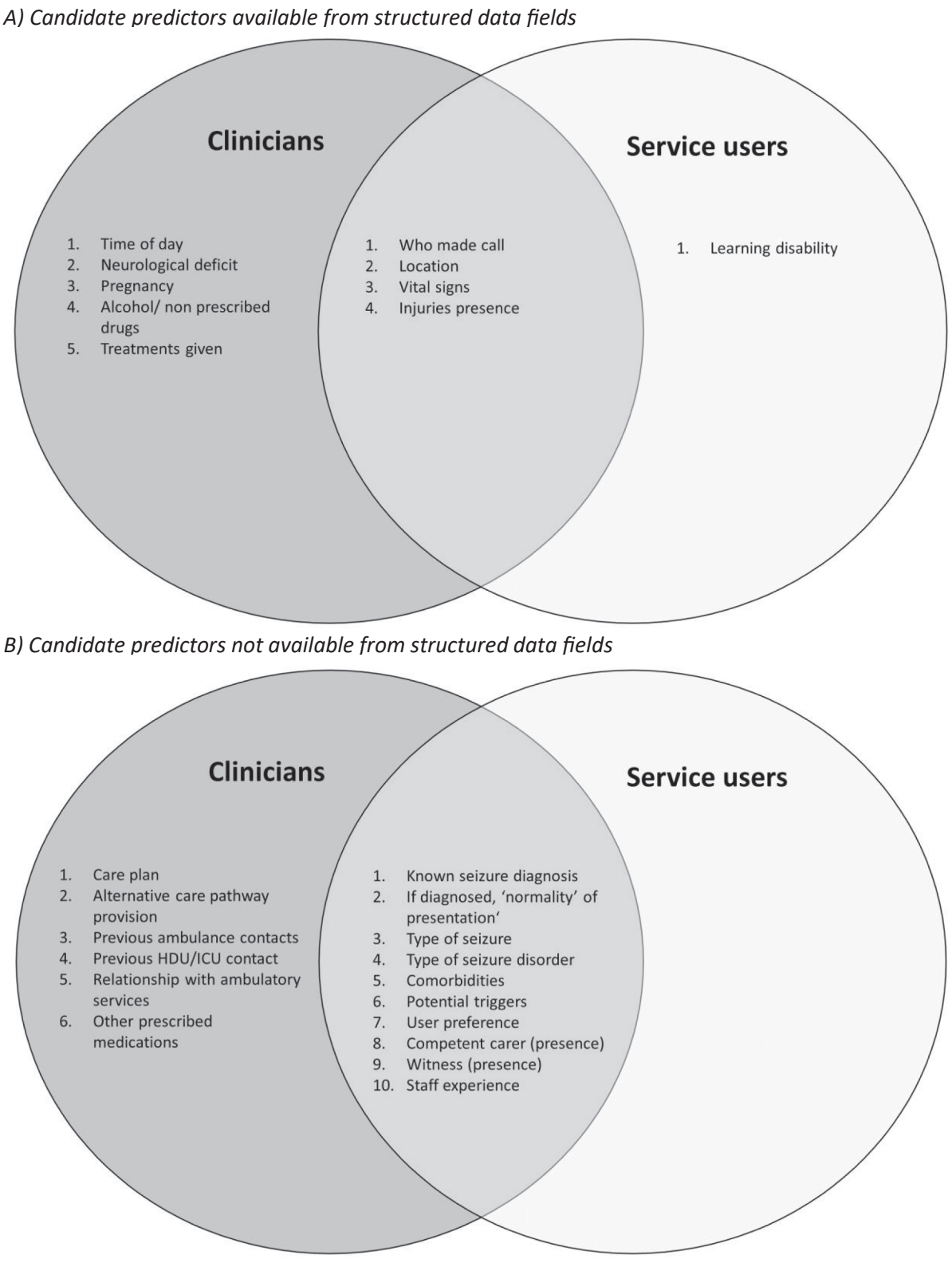

Fig. 3. Candidate predictor suggestions made by workshop participants *Notes:* HDU, high dependency unit; ICU, intensive care unit. Table 3's note provides details on the grouping of candidate predictors according to their availability via structured data fields.

necessarily need to go if it is a dissociative seizure…Its not just a list of things." (P14; Female, person with epilepsy and NEAD)

For these reasons, participants discussed whether the tool should consider a person's seizure diagnosis initially. However, most acknowledged that paramedics typically lack access to a person's medical history for this purpose. Some users shared their efforts to overcome this, while those with recent diagnoses were surprised by the lack of routine access.

Table 4
Clinicians views on tool functionality and implementation considerations.

THEME	PREFERENCE/ VIEW	ILLUSTRATIVE QUOTE/S
Format	***Paper and electronic***	*"So if it's something that is workable on paper and can go in a essentially a pocket book…and can also be done digitally and embedded into an electronic patient record too - I'd say both." (P28, Male, paramedic)*
	Electronic only	*"pieces of paper are very much getting phased out in my service. There's a little box of them that sit in the side of the ambulance door and rarely move…I think it would have to be accessible on electronic device." (P47, Male, paramedic)*
		"…the last thing I wanted to say was electronic. We need to save the planet." (P43, Male, paramedic)
	Whether paper or electronic depends on complexity of tool	*"…if its going to be something that needs…interaction…it can't really be a paper based or, you know, just a an image based kind of tool." (P47, Male, paramedic)*
Number of variables	***6–10***	*"…a maximum of maybe 10 [pieces of information to input]. Six or seven is…great, but perhaps I wouldn't go over 10." (P28, Male, paramedic)*
		"…if it's going to take me more than about 90 s, I won't utilise it…Because…if you're in a in the back of an ambulance… the awkwardness of that would dissuade me from starting to engage in something on my iPad…." (P47, Male, paramedic)
	Tolerance relates to complexity of input	*"…sometimes it depends on the answer, what the answer to the question is. If it's a yes or no, you can have a few more than normal." (P43, Male, paramedic)*
	Automated population could be considered	*"…with our NEWS scores….it's just added up automatically from our observations. So I think if we can build it into the current patient report format…just draws the information out for you it would be much simpler and we'll be used a lot more." (P36, Female, paramedic)*
Messages to accompany estimates and support interpretation	***Use colour coding to support interpretation***	*"we do seem to like traffic light systems… green being for nothing obvious to worry about and red being for something to be concerned about… just 'cos they're simple and thats in a lot of our kind of guidance." (P36, Female, paramedic)*
	Accompany estimates with potential actions	*"…it's very nice to have kind of objective tools that give you an answer…rather than just saying now use clinical knowledge…[that] just feels like 'oh what's the point using the tool' if…it gets thrown back onto us kind of thing". (P32, Female, paramedic)*
		"…suggestions should be made, but they remain guidance, because at the end of the days it should still be your clinical decision… you've still got a choice…." (P39, Female, paramedic)
	Contextualise estimate against risk in other populations	*"…you can provide… the background risk of that person having an adverse outcome in those three days or 30 days regardless of them having had a fit anyway. So what's the chance of the general public attending the ED 3 days after they've attended once already…" (P41, Female, ED)*
	Articulate limitations of tool	*"…give the pitfalls and gives background behind it." (P50, Female, paramedic)*
How to promote use	***Recommendation within national guidelines***	*"It'll be really important that that tool is…in the JRCALC …it needs to be more than just put into the ether …it needs to be kind of 'rubber stamped'(P31, Male, paramedic)*
	Included in local ambulance service tool repository	*"…I find it a bit overwhelming like how many different tools there are… … each condition has got something extra to it that you have to remember…So I think for me like just make it really accessible… my ideal for me would be like integrated into existing systems." (P49, Female, paramedic)*
		"…in [our ambulance trust] we've got a repository…you'll get it literally on your phone…I would say they are referred to far more…" (P31, Male, paramedic)

Notes: ED, emergency department; JRCALC, Joint Royal Colleges Ambulance Liaison Committee's national guideline; NEWS, National Early Warning Score; P, participant.

> *"Is that not something they [the ambulance service] have in place? I would have thought that would have been in place 'donkeys years' ago… that sounds crazy…* (P23; Female, person with NEAD)

3.4. Outcome measures

Clinicians confirmed the outcomes' importance. However, they raised issues with regards their proposed definitions.

3.4.1. Death and recontact

They advised that the significance of death and service recontact is not equivalent and so alongside the combined risk estimate, they said it would be prudent to articulate the proportion experiencing each element:

> *"…I think if you're gonna use in the tool the words 'death within three days' it suddenly adds a massive emphasis…on risk…there's a… difference between recontact and death…."* (P44; Male, paramedic)

With regards service recontact, clinicians advised that it would be important for those using the tool to know what types of service recontact are and are not included (e.g., whether it needs to be seizure related).

They debated the suitable time frame for events post-incident, focusing on the duration within which recontact could be reasonably linked to previous care. Opinions varied. Some suggested 24 h, others 3 days, and a minority 30 days. Some paramedics hesitated to offer suggestions, citing limited feedback on outcomes after ambulance care, hindering the formation of opinions. It was proposed that a range of estimates might be appropriate.

> *"…it would bother me less if they…recontacted at 3 days…But yeah, 24 h and under…I would say I would probably think that I've…made a mistake."* (P31; Male, paramedic)
>
> *"…3 days in the kind of the grand scheme…is probably quite a short amount of time…for us to potentially being basing our decision making on it….I think…30 day[s]…"* (P38; Female, paramedic)

3.4.2. Avoidable attendance

Concerning avoidable attendance, clinicians highlighted that a potential drawback in O'Keeffe et al.'s [10] criteria was its assumption that all recorded investigations, treatments, and admissions from ED were clinically 'appropriate.' They observed that some tests be administered for reasons beyond necessity for seizures, particularly blood tests and intracranial imaging. The former might be routinely collected to try to reduce patient waiting time. The latter could be overused due to staff misunderstanding. Clinicians stressed the importance of exploring and accounting for these issues if necessary.

> *"…tests can be done purely because somebody has arrived at the front door…might be because there's 'preloading'….might be because an F2 [trainee doctor] sees that patient rather than a consultant….Also, there's variation up and down the country…"* (P27; Male, ED clinician)

To a lesser extent, it was also noted that the time and day on which a person visits an ED might be important, since it might impact likelihood

of hospital admission:

> *"I think time of day people attend…and um day of week people attend… It's far harder to discharge someone at 3:00…in the morning, then is it at 3:00…in the afternoon."* (P33; Female, ED clinician)

3.5. Tool functionality and implementation

Clinicians provided a range of insights about their preferences. Table 4 details them.

Regarding functionality, a crucial aspect was the number of variables paramedics would input willingly, with the upper limit being ~ 10. This, however, depended on input complexity. Integrating the tool into electronic PCR systems, they noted, could eliminate any cap by allowing for 'auto-population.'.

Clinicians recommended additional features for the tool's estimates, noting that the risk tolerance of clinicians might differ from that of service users. They suggested contextualizing risk estimates, color-coding them with 'traffic lighting,' and prompting clinicians to discuss these estimates with service users.

> *"…as clinicians we're quite risk averse…the risks…we would take on behalf of patients are smaller than the risks patients…take for themselves, they're more likely to say, yeah, that's alright…."* (P41; Female, ED clinician)

After development, clinicians suggested actions to increase uptake, emphasizing the importance of national ambulance guideline recommendation and regional service endorsement. They stressed the need to optimize alternative care pathway provision due to existing disparities among areas, potentially hindering widespread use.

> *"…what's good is that if somebody comes to my ED with a seizure…they get a referral to our neurology centre and they get reviewed…you don't want to set something up that is then detrimental to care…."* (P27; Male, ED clinician)

4. Discussion

4.1. Main findings and implications

Novel KE workshops were conducted with stakeholders. These provided important insights into service user and clinician priorities for the proposed risk prediction tool and indicated actions RADOSS can take to optimise how it intends to develop it.

4.1.1. Need and anticipated benefits

The first piece of important evidence related to need and anticipated benefits. Given tools should be developed to meet an identified need, [30] it was important to find that, in line with the preliminary evidence instigating RADOSS, that stakeholders supported tool development. They articulated anticipated benefits. Paramedics hoped it could enhance support for a complex decision. Service users believed it could address knowledge gaps they perceived paramedics had which contributed to perceived over-conveyance.

4.1.2. Candidate predictors

Stakeholders were shown the information routinely recorded within structured data-fields and accessible to paramedics whilst 'on scene'. They discussed which items should be considered for testing. Ten were suggested, which clinicians also identified as being the maximum number it would be reasonable to expect a clinician to input.

Some were proposed by both users and clinicians, others were not. Some might have been possible to identify as candidates on the basis of the literature (e.g., vital signs, significant injury),[10,15,31] others could not have been (e.g., who made the call, presence of learning disability). This emphasizes the value of engaging with stakeholders and learning from their lived and clinical experience. RADOSS will seek to test all these suggestions, not least because a tool's adoption can be hindered if it fails to account for factors users consider important. [32,33].

4.1.3. Concerns

The workshops surfaced potential concerns. A starting assumption of RADOSS, aligned with the tenets of 'person-centred care', was that the proposed tool would support care decisions, not impose them. This was shared with participants via the presentation. Nonetheless, stakeholders primary concern was whether clinical judgement and patient preference would still factor in decisions. This emphasises the issue's importance to stakeholders and that going forward, RADOSS needs to better communicate the tool's assistive role.

Another reason such messaging is important relates to care plans and the seizure management instructions they contain. Should a paramedic find themselves with access to both the tool and a patient's care plan, the latter should be prioritized as it will be more individualised. However, it is noteworthy that care plans, especially ones accessible to paramedics, remain uncommon. Paramedics describe finding such items as "like striking gold".[6].

4.1.4. Outcome definitions

Clinicians clarified what adjustments should be made.

Concerning death and recontact, RADOSS proposed estimating their incidence within 3 days. Since death is rare (<1% of cases),[34] for statistical reasons, we anticipated combining it with service contact (~12 % of cases within 3 days).[35] Clinicians advised that the tool should, in providing the combined estimate, also state the proportions experiencing the two types of events to guard against inadvertently facilitating risk averse decisions.

No consensus on the suitable prediction timeframe for death/service recontact emerged. To address varying perspectives, stakeholders recommended a risk dashboard with different time frames. Consequently, the RADOSS will estimate death/recontact within 3 days via its primary analysis and 1 and 30 days via secondary analyses.

Regarding avoidable attendances, O'Keeffe's[10] criteria assumes all ED investigations and treatments are appropriate. Stakeholders noted potential overuse of intracranial imaging and full blood panel testing. The latter has not been identified before for UK EDs.[36] RADOSS needs to address these investigations' use to prevent under classification of attendances as avoidable, compromising the tool's utility. RADOSS will thus compare the proportion of conveyed incidents in the derivation dataset classified as "avoidable" when said investigations are considered *versus* when they are not. If a substantial difference (≥15 %) is observed, the avoidable attendance definition will be amended to exclude these investigations.

4.1.5. Functionality/implementation

If RADOSS can create a validated tool, stakeholders provided insights on desired functionality and strategies to enhance uptake. Suggestions encompassed embedding the tool within electronic PCR systems and utilizing colour coding for interpretation. While more detailed input, such as preferences for risk information visualization, is needed before finalizing the tool,[25] the obtained evidence is proportionate to the development stage.

4.2. Future research

Within the wider literature, information routinely recorded by paramedics within structured fields has been found to help predict other outcomes (e.g.,[37]). Whether it can help predict the outcomes of interest to RADOSS remains to be determined. Stakeholders did pinpoint challenges for RADOSS in deriving a precise prediction model. However, they also proposed additional factors, currently absent from structured data fields, for future research consideration to potentially enhance the

model (e.g., paramedic's years of experience,[38] seizure type, duration). Information on some of these might be found in the PCR's free-text section. If RADOSS indicates structured data alone is insufficient for predictions, then the case for accessing this free-text, which is complicated by its potential inclusion of patient identifiers,[39] may be strengthened.

Stakeholders proposed we test vital signs for their predictive value. Paramedics are expected to document at least one set of recordings of them. Others may be taken. RADOSS shall test both initial and any subsequent sets. If RADOSS identifies the latter as warranting inclusion in the predictive model, then future research should explore to what extent this means the tool is asking for information not available when conveyance decisions are being made. To help with this, RADOSS will quantity the proportion of cases in the derivation data set with more than one set of recordings, the typical time between them and the extent of change seen.

4.3. Strengths and limitations

The study's strengths encompassed a novel, transparently reported KE approach, efficiently engaging stakeholders in discussing complex topics. Standardized background sharing and diverse workshop group compositions were noted strengths. [40] Trade unions representing different health professions, including ambulance staff and junior doctors, undertook periods of strike action of varying durations when recruitment for our study occurred.[40] Recruitment success in the midst of this is thus notable. However, we did not recruit any nurses. This might have limited insights from the workshops. We also did not include users who presented to the ambulance service for a suspected seizure instigated by a cardiogenic event (which account for ~ 10 % of incidents).[2], nor cardiology specialists.

Qualitative data analysis employed a version of 'Rapid Analysis'. Such approaches are gaining popularity in implementation science for their efficiency,[41] delivering results in significantly less time than traditional approaches.[42,43] It proved effective for RADOSS. However, Rapid Analysis does have potential trade-offs. Its more deductive nature may not uncover all relevant findings, as indicated by Taylor et al.[43], who found that it generated ~ 70 % of the same findings compared to thematic coding. Our use of Rapid Analysis does not though, preclude other types of engagement with the data in the future.

5. Conclusions

By working collaboratively with stakeholders, this study has secured novel information that better positions the project to successfully derive a predictive model and maximise uptake of any tool ultimately based on it.

CRediT authorship contribution statement

Adam J. Noble: Writing – review & editing, Writing – original draft, Supervision, Methodology, Investigation, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Beth Morris:** Writing – review & editing, Project administration, Methodology, Investigation, Formal analysis, Data curation. **Laura J Bonnett:** Writing – review & editing, Methodology, Investigation, Conceptualization. **Markus Reuber:** Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Suzanne Mason:** Writing – review & editing, Supervision, Project administration, Methodology, Funding acquisition, Conceptualization. **Jasmine Wright:** Writing – review & editing, Project administration, Methodology, Funding acquisition. **Richard Pilbery:** Writing – review & editing, Methodology, Funding acquisition. **Fiona Bell:** Writing – review & editing, Project administration, Methodology, Funding acquisition. **Tom Shillito:** Writing – review & editing, Project administration, Investigation. **Anthony G. Marson:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization. **Jon M. Dickson:** Writing – review & editing, Supervision, Methodology, Funding acquisition, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Disclaimer

The views and opinions expressed herein are those of the authors and do not necessarily reflect those of the University of Liverpool, the RfPB programme, the NIHR, the NHS or the Department of Health and Social Care.

Appendix A. Supplementary material

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