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Protocol for the development of an evidence-based 'Best Practice Model' for Teams Managing Crisis in Dementia.

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Abstract

Background: Teams working in the community to manage crisis in dementia are available, but with widely varying models of practice it is difficult to determine the effectiveness of such teams. The aim of this study is to develop a model of best practice for dementia services managing crisis, as well as a set of resources to help teams implement this model: these will be (respectively) the Best Practice Tool and Toolkit, to improve the effectiveness of crisis teams working with older people with dementia and their carers.

Objective: To detail a protocol describing the development a ‘Best Practice Model,’ to include a Best Practice Tool and Toolkit intended to measure and improve practice delivery.

Methods: This paper describes the protocol for a prospective study which will use qualitative methods to establish an understanding of current practice to develop a ‘Best Practice Model,’ to include a Best Practice Tool and Toolkit intended to measure and improve practice delivery. Participants (people with dementia, carers, staff members and stakeholders) from a variety of geographical areas, with a broad experience of crisis and non-crisis working, will be purposively selected to participate in qualitative methodology including interviews, focus groups, a consensus workshop, and development and field testing of both the Best Practice Tool and Toolkit.

Results: Not applicable as protocol is describing a prospective study for development of a 'Best Practice Model' for Teams Managing Crisis in Dementia.

Conclusions: This is the first study to systematically explore the requirements needed to fulfil effective and appropriate home management for people with dementia and their carers at a time of mental health crisis, as delivered by Teams Managing Crisis in Dementia (TMCDs). This systematic approach to development will support greater acceptability and validity of the Best Practice Tool and Toolkit and lay the foundation for a large scale trial with TMCDs across England to investigate effects on practice and impact on service provision, and associated experiences of people with dementia and their carers. Clinical Trial: Not applicable

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Development of an evidence-based ‘Best Practice Model’ for Teams Managing Crisis in Dementia: Protocol

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Abstract

Introduction: Teams working in the community to manage crisis in dementia do currently exist, but with widely varying models of practice it is difficult to determine the effectiveness of such teams. The aim of this study is to develop a 'Best Practice Model' for dementia services managing crisis, as well as a set of resources to help teams implement this model to measure and improve practice delivery. These will be (respectively) the Best Practice Tool and Toolkit to be utilised by teams to improve the effectiveness of crisis team working with older people with dementia and their carers. This paper describes the protocol for a prospective study using qualitative methods to establish an understanding of current practice to develop a 'Best Practice Model'.

Methods: Participants (people with dementia, carers, staff members and stakeholders) from a variety of geographical areas, with a broad experience of crisis and non-crisis working, will be purposively selected to participate in qualitative methodology including interviews, focus groups, a consensus workshop, and development and field testing of both the Best Practice Tool and Toolkit.

Results: Thematic analysis will be utilised to establish teams managing crisis in dementia current working in order to draw together elements of best practice.

Discussion: This is the first study to systematically explore the requirements needed to fulfil effective and appropriate home management for people with dementia and their carers at a time of mental health crisis, as delivered by Teams Managing Crisis in Dementia (TMCDs). This systematic approach to development will support greater acceptability and validity of the Best Practice Tool and Toolkit and lay the foundation for a large scale trial with TMCDs across England to investigate effects on practice and impact on service provision, and associated experiences of people with dementia and their carers.

Trial registration: Not applicable

Keywords: dementia, carers, crisis, mental health, home management.

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Introduction

Home-orientated care is a key objective in the UK Dementia Strategy [1] to help people with dementia maintain their independence; however, fluctuations in health and the social needs of people with dementia and/or their carers can result in a breakdown of the caring process, making it difficult for the person with dementia to remain at home. This can lead to a crisis where the person with dementia may have to be admitted to an inpatient setting unless skilled management of the situation within the community can be employed. Whilst support from Community Mental Health Teams (CMHTs) or specialist dementia services exists, waiting times and indirect care pathways can make access difficult [2] at a critical time when the person with dementia may be experiencing an increase in their behavioural and psychological symptoms. A specialist, rapid access intervention service for people with dementia and carers facing crisis could be an effective support mechanism to prevent the breakdown in care at home.

Avoidance of crisis in dementia could reduce unnecessary emergency hospital admissions. An Alzheimer's Society report found that one in ten respondents sought hospital admission for their relative due to lack of access to community support [3]. Community support for people of working age is well specified, with identified teams (often called Crisis Resolution Teams) in place to avoid hospital admission, but a national survey found that only 16% of these general adult crisis teams accept people with dementia onto their caseload [4]. The availability of teams specific for older people with dementia is limited and variable, with differences in both the remit and names of older adult teams; the same survey identified only 30 stand-alone dementia or older adult crisis teams nationwide. A subsequent online scoping survey of 62 managers of Teams Managing Crisis in Dementia (TMCDs) identified wide variations in care pathways and types of services managing crisis in dementia. Such services include; Dementia Intensive Support Teams, Mental Health Intensive Recovery Teams, Dementia Crisis Support Teams, Dementia Rapid Response Teams, and Intensive Recovery Intervention Services [5]. This survey further identified variation in how services have developed and in teams' objectives in either preventing events that can lead to a breakdown in care or in dealing with the aftermath of care breakdown and preventing hospital admission. Regardless of whether a team has a preventative or management remit, services typically aim to make a cost saving by maintaining the person with dementia's ability to stay at home. In many areas however, services are unavailable and

hospital admissions are unavoidable.

A study of 9 focus groups found that people with dementia, carers and staff value a coordinated, evidenced-based approach to crisis avoidance, one which takes into account increasing dementia symptoms, carer inability to continue to provide care, deteriorating physical health of the person with dementia or family carer, unsuitability of the home environment, and insufficient community services [6]. With this in mind, and drawing on findings from the scoping survey described above [5], research proposed in this protocol, which is part of the Achieving Quality and Effectiveness in Dementia Using Crisis Teams (AQUEDUCT) programme funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-0612-20004), will lead to the development of a 'Best Practice Model' specific for TMCDs. This is necessary given the current lack of evidence to support, develop and promote such services.

Aims

The research described in this protocol aims to explore current practice and to develop an intervention (the Best Practice Tool and Toolkit) by addressing the following questions:

(1) What is current TMCD practice?

(2) What is considered 'best practice' for a TMCD?

(3) By which standards should TMCD practice be measured?

(4) What does a TMCD require to improve its practice?

Methods

The AQUEDUCT research programme is comprised of three work packages (WPs): Work Package 1 (WP1) concerning development of the intervention (the Best Practice Tool and Toolkit), Work Package 2 (WP2) involving a feasibility study for this intervention, and Work Package 3 (WP3) involving a full trial of the intervention. This paper describes the protocol for WP1 only.

The research in this work package is informed by the process for promoting service improvement developed by the US Evidence Based Practices (EBP) programme, which has demonstrated effectiveness in supporting high-fidelity implementation of a range of complex

interventions and service models [7]. Components of the EBP approach include [8, 9]:

i) Defining a model of best practice with detailed specification;

ii) Developing a means of assessing adherence to this model;

iii) Developing a package of implementation resources to support service improvement and greater adherence to the 'Best Practice Model.'

The intervention to be developed, consisting of a Best Practice Tool and Toolkit, will be generated through an iterative understanding of current practice and what is considered to be best practice in TMCDs. This work will build upon previously conducted research, namely the 'Support at Home – Interventions to Enhance Life in Dementia' (SHIELD) programme [10]. This previous study developed the Home Treatment Package (HTP), a tool for assessing people with dementia and their carers at times of crisis. It incorporates a number of components: the Threshold Assessment Grid (TAG) risk assessment [11], the Camberwell Assessment of Needs in the Elderly (CANE) assessment [12], a care planning template, a discharge planning template, exemplary case studies, and an advisory protocol. The HTP will be revised in phase 3 of WP1, as described below.

Sample

Sample sizes to be used in each phase of this research are similar to those considered sufficient to achieve data saturation in previously conducted research on older people's and working-age crisis management [6,15].

Inclusion Criteria

Inclusion criteria for this research are as follows:

TMCD staff members will have:

- been employed by the TMCD for a minimum of six months.
- been working directly with people with dementia

People with dementia will have:

- a diagnosis or probable diagnosis of dementia;
- been discharged from the TMCD within the past six months;
- the mental capacity to give informed consent;
- some recollection of the TMCD's involvement in their care.

Carers will have:

- cared for someone with a diagnosis or probable diagnosis of dementia who has received input from the TMCD within the past six months.

Recruitment and Consent

Several different groups of participants will be involved in this research and they will be recruited in various ways. NHS Trusts across England will be approached initially by a member of the AQUEDUCT research team who will explain the study to Research and Development contacts; so that the assessment of capability and capacity to complete the research can be initiated. NHS Trusts which include appropriate teams will then ascertain capability and capacity for involvement in individual phases of the research (rather than involvement in the protocol as a whole) by discussing the research with team managers. Once the team manager has agreed to their team's involvement in that phase of the protocol, individual staff members from the widest possible range of roles and bandings will be approached by the manager to discuss participation in the study.

People with dementia, carers and other staff members who work with the teams (stakeholders) will be approached initially by a member of the clinical team and asked if they would be willing to speak with a member of the AQUEDUCT research team. If they are interested in participating, they will then receive a copy of the relevant information sheet. A PPI-approved dementia-friendly participant information sheet will be created by the research team, to facilitate understanding of the research for people with dementia. Potential participants will be given up to three days to decide whether or not they wish to participate, after which point, if they indicate to a member of the clinical team that they are happy to participate, the AQUEDUCT research team member will answer any questions and discuss the time and location of the interview or focus group.

For the consensus workshop, participants will be purposively recruited based on their previous contact with a TMCD and willingness to be re-contacted regarding future AQUEDUCT research activity. A personal invitation will be sent to them with all information and details about the workshop. They will be asked to return an expression of interest to indicate their intention to attend, and consent will be taken by members of the AQUEDUCT

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research team on the day of the workshop itself.

Prior to all research activities then, a member of the AQUEDUCT research team will work through the relevant information sheet with the prospective participant, offer an opportunity for further questions, and take written consent. On signing the consent form, all participants will be allocated a unique identification number to ensure their anonymity during analysis and reporting of findings.

Patient and Public Involvement

The AQUEDUCT programme overall will actively engage with people with dementia and carers as Patient and Public Involvement (PPI) representatives. The role of PPI will be incorporated into all stages of the research: advising on study documentation and participant recruitment procedures, assisting in data collection as co-researchers, commenting on the suitability of data analysis, and taking part in the AQUEDUCT Programme Steering Group (PSG) and AQUEDUCT PPI Reference Group. In this way, every stage of the research process will be informed by service user experience and expertise, and the research will adhere to its objectives of benefitting people with dementia, carers and members of the public.

Phase 1 – Mapping Current Practice and Identifying Best Practice

This is a prospective study using qualitative methods to garner a broad understanding of the necessary elements of service provision for effective crisis management and resolution for people with dementia and their carers. The design and three constituent phases of WP1 are illustrated in Figure 1.

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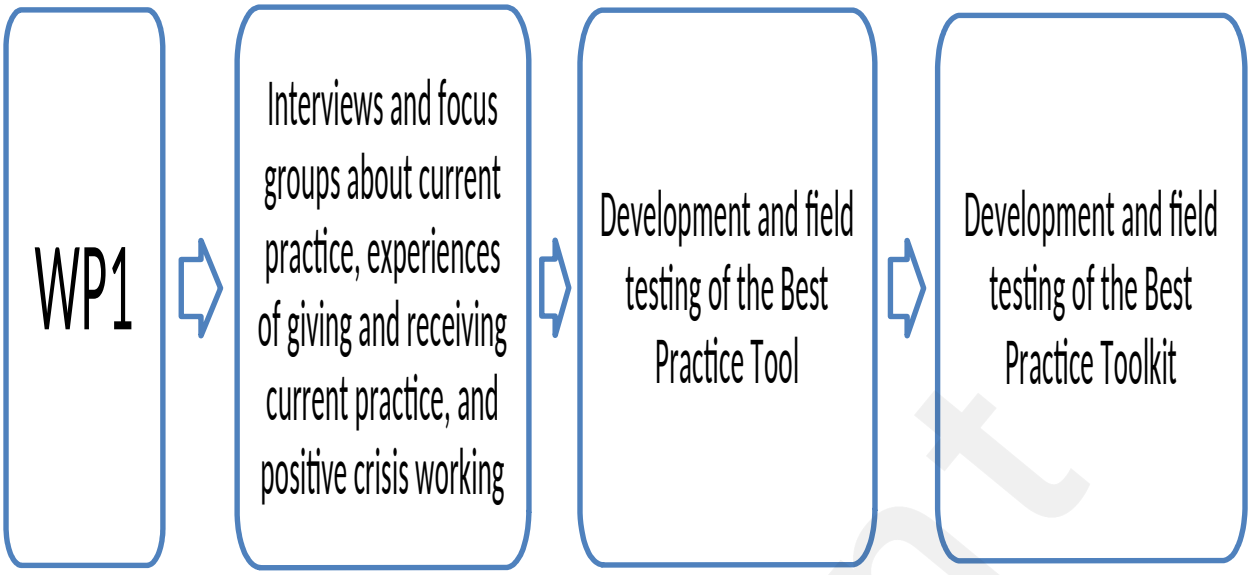

Figure 1: Design and three constituent phases of WP1

In the first phase, interviews will be carried out (following purposive sampling) to garner perspectives of people with dementia, carers, TMCD staff members, and individuals who work with TMCDs (stakeholders) on current practice and the experience of providing or receiving care. Participants will have accessed, had contact with, or worked in a TMCD to be eligible for interview. Interviews will map the scope of a service and will document team composition, geographical characteristics and practical operation, links with other services, communication and decision-making, and service evaluation processes. The interviews will result in collection of information concerning clinical processes and procedures, together with information on what works well and what does not work well in order to consider best practice and possible facilitators of best practice.

Semi-structured focus groups will then be carried out with people with dementia, carers, TMCD staff members, and individuals who work with TMCDs, to consider best practice further and to identify what facilitates positive TMCD working. These groups will ascertain the set-up of TMCDs, barriers and facilitators to positive working, and examples of good practice. Data will be analysed using thematic analysis to develop items for the ‘Best Practice Model.’

60 participants from five TMCDs will be recruited for individual interviews. AQUEDUCT team researchers and PPI co-researchers will then facilitate nine focus groups of between four to six participants each.

Incorporating two different stages of qualitative exploration (individual interviews and focus groups) will be the most appropriate methodology to enable understanding of current practice and identification of best practice, as it will provide opportunity to elicit both individual and context-specific characteristics [13]. Through this iterative process, it will be possible to recognise key characteristics in dementia crisis team working, to increase the validity and richness of findings.

Phase 2 – Development and Field Testing of the Best Practice Tool

A Best Practice Tool will be created, to be used by TMCDs to measure their current practice and the extent to which they fit the 'Best Practice Model.' The process of testing the Best Practice Tool will be derived from the CORE study procedure, a National Institute for Health Research (NIHR) funded programme that developed a fidelity scale of best practice for working-age Crisis Resolution Teams [14]. The development of the Best Practice Tool detailed in this paper aligns with the development of the CORE Fidelity Scale.

Evidence Based Practice principles [8,9] will be used to draw together evidence gathered during the qualitative phase of this protocol to form a 'Best Practice Model' and to develop the first iteration of the Best Practice Tool. A consensus workshop will revise and validate the Best Practice Tool to create the next version. The workshop will involve at least 25 attendees, including PPI representatives, TMCD staff and managers, National Health Service (NHS) staff from primary and secondary care who interface with TMCDs, senior Trust managers, commissioners, and academics.

The revised version of the Best Practice Tool will then be field tested with 12 TMCDs and five older people's CMHTs which do not have a dedicated dementia crisis response function, to establish face and content validity. Comparing Best Practice Tool scores for these two types of teams will provide construct validity, ensuring that the practice quality of crisis teams, rather than the practice quality of generic mental health teams, is measured by the Best Practice Tool. Each item of the Tool will specify various types of evidence that can be inspected to determine whether the team meets the scoring criteria, and will be weighted so that the team will receive an overall Best Practice Tool score out of 100.

Each team will take part in a review day during which three reviewers (a member of the AQUEDUCT research team, a PPI member, and a clinician who works with people with dementia) will rate the practice of the team according to the 'Best Practice Model'. Evidence will be collected from various sources including; interviews with team members, team managers, staff from other services who work closely with the teams, people with dementia and carers; case note and paperwork reviews; and a visual check of the team base. Reviewers will compile and evaluate all data throughout the day to agree on a Best Practice Tool score. The face and content validity of the Best Practice Tool will be assessed using these data.

The Best Practice Tool will enable identification of 'gaps' in each TMCD's current practice that can be filled by use of the Toolkit, development and implementation of which is outlined below.

Phase 3 – Development and Field Testing of the Best Practice Toolkit

The Best Practice Toolkit will include the HTP developed during the SHIELD study, referred to above. A briefing will be carried out with two senior TMCD staff members to determine suitability for use and ease of completion of the HTP, the purpose being to modify the HTP where required before it is incorporated as an element of the Toolkit. The briefing will involve one day of training for the TMCD staff members on the purpose and application of the HTP (the latter incorporating case study examples), then staff members will draw on their own clinical experience to complete the HTP and provide feedback on the process of doing so to the AQUEDUCT research team.

Additional elements of the Best Practice Toolkit will be determined by drawing on information generated from the qualitative work to identify elements of best practice, considering in particular how teams can best fulfil criteria laid out in the 'Best Practice Model.' The Toolkit will promote best practice through the use of templates and documents that can be mapped onto the Best Practice Tool.

Five TMCDs will field test the Best Practice Toolkit. Staff members from these TMCDs will receive online training in the use of the Toolkit, and two AQUEDUCT team researchers will then visit these staff in their place of work to discuss their Best Practice Tool score and

areas for improvement. The TMCD staff members will agree with the AQUEDUCT team researchers which elements of the Toolkit they will implement over a period of four weeks, and after this time they will provide feedback on the suitability of those elements for use in their team. During the four week period, an AQUEDUCT team researcher will conduct weekly telephone calls with the TMCD to record usage of the Toolkit elements. Following receipt of all feedback from the five TMCDs, the Toolkit will be amended for future use in the feasibility study.

Governance

All information will be treated as confidential, with adherence to the NHS Code of Confidentiality [16], General Data Protection Regulation [17] and Good Clinical Practice (GCP) guidelines [18]. All insurance and indemnity arrangements will be covered by the study sponsor, Nottinghamshire Healthcare NHS Foundation Trust. Ongoing progress of the research will be monitored by the Programme Management Group (PMG) comprised of the co-applicants who were awarded the NIHR grant, and a PSG which will be independent of the sponsor and other interested parties, in association with the Chief Investigator and Programme Manager both of whom are Consultant clinicians. Overall, this research will benefit from and be guided by experts from the fields of older adult psychiatry, clinical psychology, mental health nursing, social work, and occupational therapy due to the clinical background and expertise of the co-applicants on the grant, as well as voluntary services for older people, PPI, and research methodology and dissemination.

Results

Interview and focus group data will be analysed using the six phase thematic analysis method [19], to establish current TMCD working and to draw together elements of best practice. This analysis process involves researchers (1) becoming familiar with the data, (2) generating initial codes from the data, (3) searching for themes, (4) reviewing themes, (5) defining and naming themes, and (6) writing up the thematic analysis. Data will be organised using the framework method [20], to assist in comparison of data within themes and across participants. Results will inform items for the evidence-based ‘Best Practice Model’ and a first version of the Best Practice Tool will be developed using evidence-based practice principles [21]. Feedback data from the reviewers, teams and others who take part

in the review days will then be used to evaluate the usability and feasibility of the Best Practice Tool, and outcome data from this version will be compared between TMCDs and non-crisis teams, to ensure that the Best Practice Tool is specific to TMCDs as opposed to generic older adult mental health teams.

Discussion

This protocol presents extensive qualitative methods and an iterative approach to enable accumulation of in-depth knowledge about the characteristics, processes and policies of TMCD working. The use of both semi-structured interviews and focus groups will mean that decision-making processes and rationales given for ways of working can be explored fully [13] and incorporated into an evidence-based 'Best Practice Model.'

Integral to this research is the role of people with dementia and their carers, ensuring that their views and experiences will be incorporated. In particular, it is proposed that interviews and focus groups will be carried out with people with dementia; so that this research does not assume what constitutes best practice on their behalf. PPI and research co-creation are built into this protocol, to reduce the possibility of this research becoming detached from TMCD working in practice, as experienced by those who receive it.

As this work will make use of participants' retrospective accounts of TMCD involvement, it is possible that in the case of people with dementia, memory difficulties may lead to gaps in details given. Carers' interviews will also be included to compensate for this; however, as general impressions from people with dementia (to include their residual emotions generated by TMCD input) are considered crucial to the development of a 'Best Practice Model' that takes into account 'softer' aspects of care, such information will be collected whenever possible

The research outlined in this protocol will result in the development of a 'Best Practice Model' for TMCDs and a Best Practice Tool by which fidelity to this model can be measured. To date, no such model exists, and dementia crisis working has been inconsistent and the quality of care delivered variable and difficult to measure due to the lack of quality indicators and lack of standardisation across services. This research has potential to address this

current variability in practice. Such variability may be in part due to the variety of team models existing at present, ranging from those that are dementia-specific, to those serving older people generally (and which thus also have a remit for functional disorder), to those which serve adults of all ages who are experiencing a mental health crisis. The ‘Best Practice Model’ will be promoted through the Best Practice Tool and Toolkit which (respectively) will provide teams with a benchmark by which to measure their practice specific to dementia working and the resources required to improve delivery of their practice. Ultimately, it is expected that the Best Practice Tool will be suitable for self-completion by TMCD staff who will then be able to identify their own practice areas requiring improvement; this approach will be trialled in a subsequent feasibility study. As the ‘Model of Best Practice’ is based almost exclusively on stakeholder opinion rather than on objective empirical evidence, its validity must be confirmed by establishing the relationship between good model adherence and better outcomes; this will be explored in a future large scale trial.

List of abbreviations

AQUEDUCT – Achieving Quality and Effectiveness in Dementia Using Crisis Teams

CANE – Camberwell Assessment Needs in the Elderly

CMHT – Community Mental Health Team

EBP – Evidence Based Practices

GCP – Good Clinical Practice

HTP – Home Treatment Package

NHS – National Health Service

PMG – Programme Management Group

PPI – Patient and Public Involvement

PSG – Programme Steering Group

TAG – Threshold Assessment Grid

TMCD – Team Managing Crisis in Dementia

WP – Work Package

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Declarations

Ethics approval and consent to participate

Ethical approval was given by the West Midlands (Black Country) Research Ethics Committee (REC) (reference: 16/WM/0273) on 4th August 2016 and HRA approval was given on 24th August 2016.

Consent for publication

Not applicable.

Availability of data and materials

Not applicable.

Competing interests

Not applicable.

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Author contributions

All authors have contributed to the drafting of this manuscript and have revised and approved the final version.

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Disclaimer

The views expressed in this paper are those of the authors and not necessarily those of the NIHR, or the Department of Health and Social Care.

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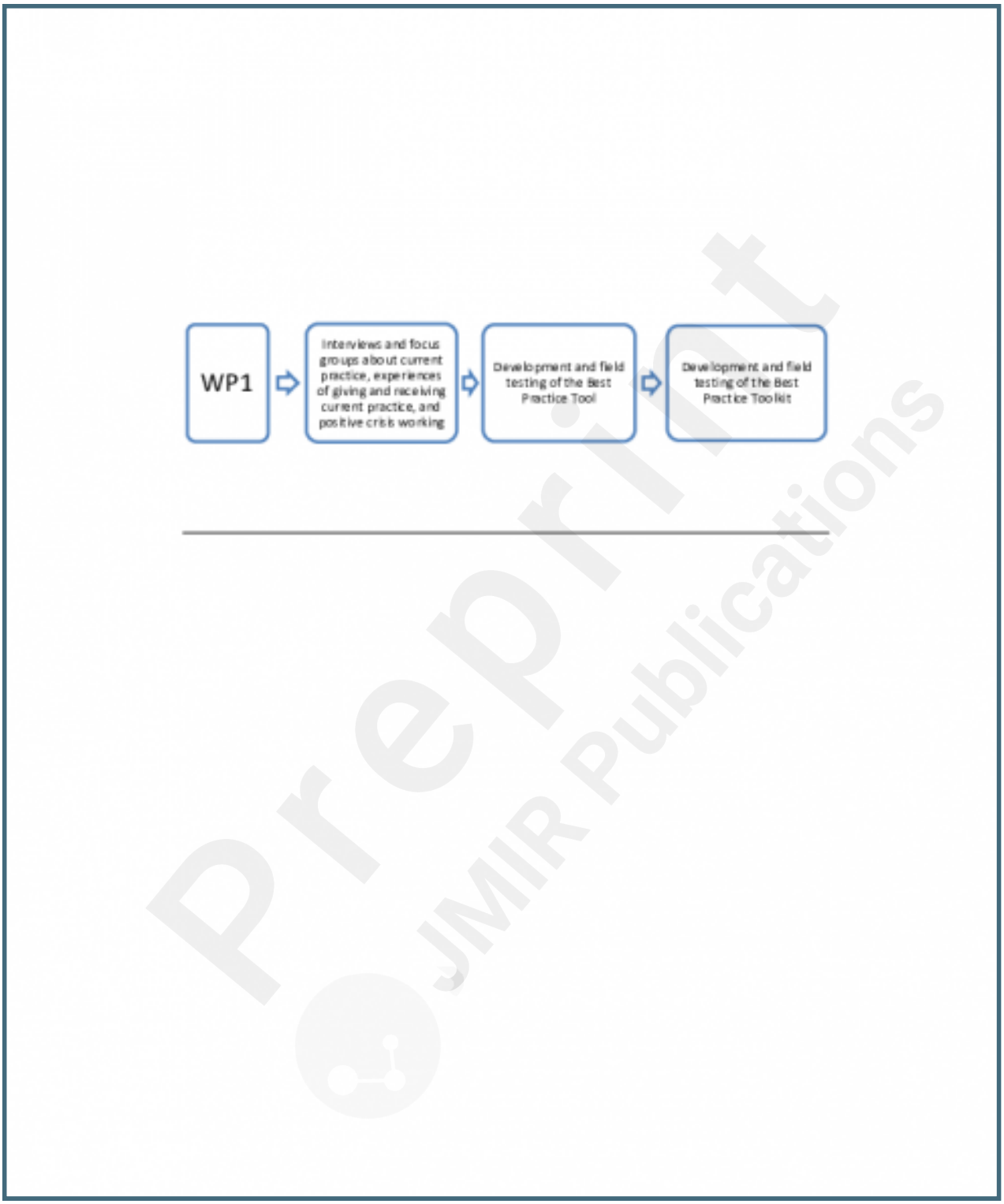
Design and three constituent phases of WP1.



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