

1

An Introduction to Nursing Research

1.1 Introduction

In this chapter, we will introduce you to what nursing research is, why it is important, how it is approached, and how to develop research questions that you may want to ask about nursing practice. By doing so, we also aim to empower you to recognise nursing practice that is ritualised or entrenched, rather than evidence based, and to be able to identify whether the evidence underpinning a particular practice is outdated or weak. These skills will allow you to see how research influences and informs our nursing practice – why we do the things we do and the ways that we do them. This will also equip you in critiquing care delivery and in ascertaining whether we could produce better outcomes if we had stronger evidence to support our nursing practice.

Reflective Activity 1.1

To begin, an important question to consider is, '*What is research?*' Make a list of everything you currently know about research and use this to create your own definition.

1.2 What Is Research?

A good place to start when exploring what we mean by ‘research’ is to consider how research differs from other sources of knowledge that may inform nursing practice, such as beliefs, tradition, intuition, habit, and common sense. In the United Kingdom (UK), research is defined by the Research Excellence Framework (REF) as ‘*the process of investigation leading to new insights, shared effectively*’ (REF 2019). Research can also be defined as the ‘*study of phenomena by the rigorous and systematic collection and analysis of data*’ (Parahoo 2014, p 30). There is also a difference between collecting information, for example through an audit, and undertaking research. So, compared to other sources of knowledge, research is a systematic way of knowing, in which the methods used must be available for scrutiny. This emphasis on a systematic and transparent approach gives researchers their particular claims to knowledge. Research systematically investigates ideas to increase knowledge and devise new interventions and new and better ways of working by establishing or confirming facts, reaffirming previous knowledge, solving problems, and supporting or developing new theories. In nursing, we can then use this new knowledge to inform our practice, by providing the evidence to support our evidence-based practice (EBP).

Reflective Activity 1.2

Discuss with your colleagues why they think research is important to nursing.

1.3 Why Is Research Important to Nursing?

So far, we have discussed what research is, but why should research command attention in our nursing practice? As registered nurses it is important that we understand the need to base our decisions about patient care on contemporary research evidence, factoring in the relevant legal, regulatory, and governance requirements and specific policies and ethical frameworks. This does not mean that nurses should always be engaged in research, but there is an expectation that we engage in practice which

is based on the best available evidence. To do this effectively requires that we understand the different approaches and methods of research and that we have the skills and knowledge to be able to review and apply critical appraisal and critical thinking to different sources of knowledge around particular topics of relevance or interest. Ultimately, to identify what good practice is requires us to be able to test, measure, and evaluate it and so we need to know how to go about doing these things through the use of research.

Nursing research is integral to nursing practice in a diverse range of areas including education, ethics, clinical skills, and clinical practice, and nurses engage with research for several reasons. If you have ever used healthcare services, then you are a user of research. You are also likely to be a consumer of research through reading research papers, writing literature reviews, attending lectures or seminars, or when learning in practice. You are also using research when following clinical guidelines. Nurses can also be promoters of research, by providing evidence-based information to patients and service users, through supporting peers and colleagues to update their practice, and by developing and disseminating evidence-based guidelines and policies. Nurses might also be participants in research and the experiences and involvement of nurses, including nursing students, in research studies helps to inform the nursing evidence base. Nurses' involvement in research can also help to improve communication within nursing practice, build relationships and partnerships with other practitioners and disciplines, and help to further develop the critical evaluation of evidence-based nursing care. Involvement in research can also help nurses to develop competence and confidence in practice.

There are many different ways in which nurses might be involved in research, ranging from developing one's awareness of research methods and applying research evidence to clinical practice, through to contributing to research studies, and on to undertaking and leading research projects or a programme of research. All these approaches help to develop and promote a positive research culture in nursing. You may also be, or indeed aspire to be, an activist in research. This involves taking part in the design, conduct, and dissemination of research studies – and again, there are many roles a nurse can fulfil in these areas. Activists in research may be driven or inspired by personal, professional, organisational, or societal issues that lead them to develop

and conduct research studies and programmes of research. For example, at a personal level, there may be phenomena faced by nurses in their own lives, or issues faced by service users, patients, or clients that lead to the development of research studies. Nurses can also encounter professional problems or challenges that generate research ideas, helping to advance the nursing profession and improve patient care. Organisational issues may also be evident, such as the ongoing evolution and development of the diverse roles of registered nurses, and changes to the way care is organised and delivered, including the continuing drive to advance nursing services in community-based care. There are also changes to the way nurses are educated and our continuing professional development needs. As nurses take on different challenges and demands of care, this requires strong supporting evidence, generated through research. There are also broader societal issues that warrant attention through nursing research, such as health inequalities, climate change, sustainability, and the impact of innovative technology such as artificial intelligence. Leaders in research set the agenda for research in areas of practice, facilitate and support others to undertake their research, or lead in other ways at both national and international levels. While this may seem a long way away for you at the moment, it is definitely something that we would advocate that you aspire to!

1.4 Evidence-based Nursing

As we have discussed, research can provide evidence for clinical practice, healthcare service organisation and delivery, and the patient and service user experience. Research can also help us to evaluate and innovate new interventions, policies, and practice. And of course, as with all contemporary healthcare, nursing practice should be based on the best available evidence, and this evidence should be robust and reliable. EBP (and thus evidence-based nursing) is a key requirement to support safe, effective patient care. There have been a range of formative definitions offered for this concept, including:

“The conscientious, explicit and judicious use of current best evidence in making decisions about the care of individual patients”
(Sackett et al. 1996, p 71).

This definition of evidence-based healthcare was later updated to incorporate what we know as the three pillars of evidence, which requires nurses and other healthcare professionals to combine the best available research evidence with clinical expertise and patient values and preferences to guide our decision-making, as outlined below and in Figure 1.1:

“Evidence-based medicine (EBM) is the integration of best research evidence with clinical expertise and patient values. [...] By patient values we mean the unique preferences, concerns and expectations each patient brings to a clinical encounter and which must be integrated into clinical decisions” (Sackett et al. 2000, p 1).

*“Decision making that considers the feasibility, appropriateness, meaningfulness, and effectiveness of healthcare practices [...] may be informed by the best available evidence, the **context** in which care is delivered, **the individual patient** and the **professional judgement and expertise** of the health professional informs this process.”* (Jordan et al. 2019)

We have established that evidence-based healthcare and thus evidence-based nursing focuses on the need to use interventions and conduct practice that is supported by the best-quality and most up-to-date evidence or knowledge available. However, an important word here is ‘judicious’ – we need to use the best available quality evidence *with*

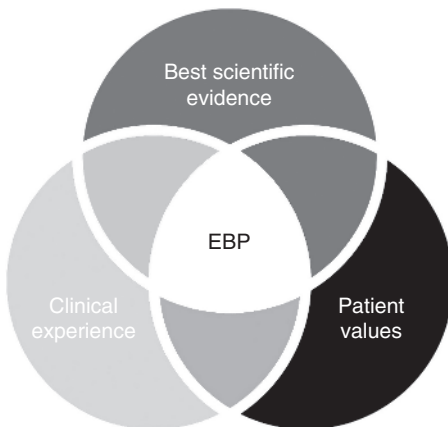


Figure 1.1 Determinants of evidence-based practice (EBP).

judgement, taking into consideration individual needs and preferences. Adopting an evidence-based approach to our nursing practice will help reduce (and hopefully eliminate) the risk of ritualised care or custom and practice. Evidence-based nursing is important as it allows us to translate research evidence into everyday practice to provide the best possible patient care and explain the rationale for this care to patients, carers, and their loved ones. We can also justify the care provided if challenged or questioned and this evidence-based approach reduces the risk of any litigation or perceived negligence in care. There are also professional reasons why nurses should engage with research evidence and research practice. For example, the importance of evidence-based nursing is recognised and emphasised by nursing regulatory bodies, including the Nursing and Midwifery Council (NMC) in the UK, with evidence-based skills and knowledge being a professional requirement for nurses working in the UK and for nursing students.

Reflective Activity 1.3

Consider the potential risks associated with applying poor-quality research evidence to healthcare delivery and nursing practice.

Applying poor-quality research evidence in healthcare can have disastrous consequences for patient care and outcomes. It can also damage the reputation of healthcare providers and erode trust between service users and professionals. There are several infamous examples of ‘bad research’, one of which is the research conducted by Dr. Andrew Wakefield and his colleagues, published in the *Lancet* in 1998 and since retracted. In this study, Wakefield suggested that the measles, mumps, and rubella (MMR) triple vaccine may have been linked with the development of autism in children. Whilst Wakefield’s research was subsequently debunked due to the poor methods used and the spurious nature of the conclusions, this incident put doubts into people’s minds about vaccinations that continue to this day. These research findings were widely reported in the mainstream media, resulting in many parents choosing not to vaccinate their children, and subsequently unvaccinated children developing one of the three diseases either as children or later in life. Whilst this is a rare and extreme example of poor-quality research, it does help to emphasise that nurses and other healthcare professionals

must be able to understand how to critique research evidence to ensure that our practice is based on the best available evidence and not on poorly conducted, dubious research. *A Rough Guide to Spotting Bad Science* by Andy Brunning (2014) (www.compoundchem.com) is a useful online resource to help you to filter through the good and the not-so-good claims made in health research.

1.5 Research Methodologies: An Overview

Methodology and methods are two words that are synonymous with research and are sometimes, incorrectly, used interchangeably. However, it is important to note that they do not mean the same thing. Methodology refers to the philosophical and theoretical basis through which the phenomena of interest are investigated and analysed. Methods refer to the specific techniques used by researchers when investigating and analysing these phenomena. Therefore, the methodology informs the researcher's approach to the research by providing a structure and a guide to the research design, data collection techniques, and data analysis used to examine an issue, whereas the method relates to the specific techniques used by the researcher to collect and analyse the data – for example, questionnaires or interviews and statistical or thematic analysis. When designing a research study, the methodology usually dictates the methods it may be helpful to.

1.5.1 Deductive and Inductive Approaches

Inductive and deductive reasoning are two different approaches to research, which are more about the overall strategy of the research rather than specific methods or methodologies. Researchers can adopt either approach, usually dependent on factors such as the research question and the available data. Deduction is a form of reasoning which can be explained as working from the general to the specific – a top-down approach. The researcher will begin with a theory about the topic under investigation before narrowing it down. This can be done by developing a hypothesis and then testing this hypothesis by collecting and analysing data, which allows the initial theory to be confirmed or disproved.

A good example of a deductive approach is that of Chang et al. (2021), who examined the impact of a simulation-based mobile app on student learning. The authors began by developing a general theory and a

corresponding set of hypotheses that focused on student learning and satisfaction. They then went on to test whether these were supported by analysing outcomes among a group who used the mobile app (the intervention group) compared to those who used usual paper-based learning (the control group). Through analysis of the findings, the team demonstrated use of a deductive approach to confirm a theory-based hypothesis.

In contrast, induction is exploratory and allows us to build theory from data by moving from specific observations to broader generalisations and eventually to developing a theory. A researcher will begin by generating specific observations or data and will then try to identify patterns, themes, or relationships within the data to develop general theories or explanations about what they have observed. This approach is often linked with qualitative research, where data and observations from individual participants are analysed and subsequently drawn together to help form a general theory regarding the phenomenon being studied. For example, Alteren et al. (2021) conducted a qualitative study of nurses' strategies for coping with interruptions during medication administration. After interviewing 19 nurses and analysing the interview data, they identified 'meaning units' which they subsequently developed into a coherent understanding to inform the development of theory.

1.5.2 Quantitative and Qualitative Research Methodologies

Our discussion about inductive and deductive approaches to research leads us to the two broad research methodologies: quantitative and qualitative. However, these should not be viewed as binary opposites, but as two different, distinct but complementary approaches to conducting research.

Early forms of research originated in what are known as the natural sciences such as physics and chemistry and were concerned with investigating things that could be measured and observed objectively so that these measures could be repeated by other researchers. This is known as quantitative research, which, broadly speaking, is associated with numerical data. Quantitative research is concerned with the systematic investigation of phenomena, the objective being to develop and use theories and/or hypotheses which relate to the natural world. Quantitative research is concerned with questions such as 'how much', 'how many', 'how often', and 'to what extent'. It is characterised by objectivity and generally involves large numbers of participants with the aim

of generating valid, reliable and generalisable data. This approach is well suited to establishing cause and effect relationships.

More recently, researchers became interested in studying human behaviours and the social world, but it proved difficult to explain this in simply measurable (quantifiable) terms. Whilst measurements can provide data about how often people behave in a certain way, or how many people perform certain actions, these data cannot adequately answer the question ‘*why?*’ Research which attempts to increase our understanding of why things are the way they are in the world and why people act the way they do is called qualitative research. Adopting a qualitative approach allows researchers to develop explanations of social phenomena through the collection, analysis, and interpretation of data through a more subjective approach to methods such as in-depth interviews, focus groups and observations of people. Qualitative research is concerned with finding answers to questions which begin with ‘how’, ‘why’, and ‘in what way’ to explore what is lived reality. Qualitative researchers do not claim that people’s experiences and perceptions are universal, replicable, or generalizable – instead, the aim is to generate rich, detailed, and nuanced data that contribute to an in-depth understanding of the context. Although subjective by nature, qualitative researchers also strive to ensure rigour through credibility and trustworthiness of the research process and findings. Qualitative research tends to be associated with ‘transferability’, which refers to the extent to which research findings may be applicable or relevant to other contexts or settings beyond the specific research context.

Reflective Activity 1.4

List the characteristics of quantitative research and qualitative research.

Invariably, comparisons are drawn between qualitative and quantitative methodologies and there are some key differences to consider. The focus of qualitative research tends to be wider ranging than the narrow, specific focus of much quantitative research, with qualitative studies often having a broader question, rather than the precise type of question associated with quantitative research. The nature of evidence generated by qualitative data is seen as subjective, compared to the objective evidence required for quantitative studies and this is aligned to the detached relationship

between researchers and participants in quantitative research, compared to the more involved relationship between participants and researchers seen in qualitative research. Data collection methods and tools used in quantitative research are concerned with issues of accuracy, reliability, and validity, whereas qualitative researchers are very much part of the data generation process and in effect become the data collection tool. The approach taken by qualitative researchers is more flexible and adaptable and may evolve as the research study develops, with issues such as validity and reliability (see Chapter 4) not being of specific concern to the researcher. Similarly, whilst quantitative research is concerned with risks of bias, this is not the case for qualitative researchers who are more focused on issues of trustworthiness, credibility and dependability. Sample sizes for quantitative research should be large to reduce bias and increase statistical power, which is also linked to the generalisability of the results of a study. The results from quantitative studies are usually expressed numerically. In contrast, qualitative research samples are smaller than quantitative studies and are usually purposive in that the researcher seeks to involve participants who can provide detailed insights into the area of inquiry. Qualitative researchers are not concerned about generalisability but rather the ‘transferability’ of the findings. Data tends to be expressed as words with the aim of generating rich, detailed findings.

1.5.3 Methodological Congruence and Research Questions

Put simply, the term ‘methodological congruence’ refers to the fit between the research question, the chosen methodology and the methods employed in conducting the research.

The wording of a research question generally indicates the need to employ a particular research methodology. For example, a qualitative question is usually concerned with trying to understand the experiences and meanings that people have about the concepts in the research question. Qualitative research questions, therefore, often ask about people’s lived experiences, individual experiences, understandings, meanings, and stories and so qualitative questions commonly begin with words such as ‘how,’ or ‘what.’ If the research is aiming to describe something, the question may be ‘*What happens...?*’ If aiming to understand something, the question might be ‘*What is the meaning to people of what happened?*’ If the aim is to explore a process, the question might be ‘*What happens...over time?*’

A quantitative question usually expresses a relationship between variables. There are various approaches to quantitative research depending on the research question and associated aim. For example, descriptive studies are concerned with what is happening (e.g. how common is recreational drug use among university students?). Correlational questions are concerned with the relationship between variable X and variable Y , and the strength of this relationship (e.g. what is the relationship between academic performance, and recreational university drug use?). Impact studies examine the impact of a change in X on Y (e.g. has a drug awareness programme had any effect on the level of recreational drug use among university students?). A quantitative study may also contain a hypothesis, which is a conjectural statement of the relationship between two or more variables that can be measured (but more of this in Chapter 4).

Reflective Activity 1.5

Return to Reflective Activity 1.4 and build on your lists of what characterises quantitative research and qualitative research.

1.5.4 Formulating the Research Question

One of the most important steps in any research project is to identify a clear aim and then formulate a research question. This is important as all that follows in the research process is dependent on the research question. The research question should be clear, focused, specific and unambiguous, identifying what you intend to research and how, and should include a specific aim for the research. A well-formulated research question defines the study and provides clear focus and direction throughout the research process, identifying the scope and boundaries of the research, which in turn helps to inform the study design, methodology and methods. When formulating a research question, it is helpful to consider the following points:

- *Interest:* This should influence the choice of research question – if you don't find the topic interesting it is difficult to be motivated throughout the research especially if difficulties arise during the process.
- *Size, scope, and resources:* The research question must have enough scope to allow new knowledge to be generated but, at the same time,

the research question should not be too broad as this may result in a project which may lack direction and require resources that are unrealistic.

- *Measurement of concepts:* It is important to be able to measure that which you wish to investigate. For example, if you wanted to measure the extent to which lung cancer affects a person's quality of life, you need to find a way of measuring quality of life. If you propose to conduct qualitative interviews with people about this experience, you should think about what questions you might ask and what these questions would be based on.
- *Level of expertise:* During your project you will typically learn new things, such as new statistical techniques and the use of software to aid in this process or developing qualitative interview skills. However, try to avoid setting overly ambitious goals. For example, it is important to ensure that if you wish to use an advanced form of statistical analysis someone in your team will be able to support you with this, or with qualitative methods it may be helpful to perhaps test and refine your interview technique with colleagues or friends first.
- *Availability of data:* You will need to have access to potential participants (or data sources) that will help you answer your research question.
- *Ethical issues:* Care should be taken to ensure that all research participants are treated ethically. Often, this is the most crucial of all issues as complex ethical challenges and associated ethical approvals can sometimes take time to resolve.
- *Relevance:* The research question needs to be relevant to your area of practice and should also add to the existing knowledge base.
- *Existing research:* When developing a research question, you need to find out what is already known, identify any gaps in the evidence and make an argument for your own proposed research. A literature review can help you with this, and we will discuss this further in Chapter 2.

Reflective Activity 1.6

Make a list of potential research questions that you would like to address. Now rank the list of possibilities in relation to how viable each question is. Reflect on why you chose to rank the questions in that particular order.

When thinking about a research question, it is also helpful to ‘problematised’ the topic. Considerations include: How do you know it is a problem? If it is a ‘hunch,’ what sources of information could you access to move from this subjective perception to an objectively defined problem? Identifying the research topic can also be supported by considering the following prompts (the four Ps): People, Problems, Programmes, Phenomena.

Frameworks can assist in generating a question for different types of research that is specific and focused. PICO is widely used in healthcare and stands for:

- *Patient/Population*: Who is the research about? This might include age, ethnicity or gender, or people with a particular health condition.
- *Intervention*: What is the nurse doing? This could be an intervention to diagnose, prevent or treat.
- *Comparison*: What is the intervention being compared to? (Note – this element isn’t always present).
- *Outcome*: What is being measured, how can we tell whether the intervention had any effect?

PICO is very helpful for developing questions about interventions, but nursing questions are not always about interventions. This is where other tools such as SPICE and SPIDER can prove useful. SPICE is often used by researchers in healthcare, social care, and public health. It stands for:

- *Setting*: Where? This could be a location, or a healthcare setting such as a paediatric ward or a GP surgery.
- *Perspective*: Who? This might be service users, or it could be a specific group of professionals such as school nurses or health visitors.
- *Intervention*: Just like in PICO, though the concept of intervention could be broader here and include environmental factors.
- *Comparison*: Again, just like PICO.
- *Evaluation*: How is the impact of the intervention being measured?

SPIDER is particularly useful for qualitative or mixed methods research which investigates people’s experiences of or attitudes towards something. It stands for:

- *Sample*: The participants in the research.
- *Phenomenon of interest*: What is it that the research will look at? This should be something which people can experience or have opinions about.

- *Design*: How the study will be conducted.
- *Evaluation*: What is being measured or evaluated? With SPIDER, this may be something subjective such as beliefs or understanding.

1.6 Research Aims and Objectives

When developing aims and objectives there is a risk that these two aspects of the research study can be conflated. To clarify, the aim of the research is the overarching goal – for example, to ‘discover,’ ‘generate,’ ‘explore,’ ‘identify,’ or ‘describe.’ The objectives are the steps that will need to be taken to achieve the overall aim, for example: *to conduct a review of the literature, to conduct interviews with..., to analyse data using..., to synthesise the existing literature with the findings of the study and to make recommendations based on the research findings.*

1.7 Prioritising Patient and Public Involvement

Patient and public involvement (PPI), or knowledge user involvement, is key to ensuring that the research question and its associated aims and objectives are meaningful. Depending on the study, PPI can also benefit the conduct of the study, for example through the use of peer researchers. In addition, PPI can be tremendously helpful in supporting meaningful dissemination of the research findings.

In the context of PPI, the term ‘patient and public’ includes everyone who uses healthcare services or may do so in the future. The same applies to the term ‘knowledge user’ but an additional consideration that this term introduces is the notion of healthcare staff as knowledge users. As well as involvement, additional terms that you are likely to encounter in relation to PPI are ‘participation’ and ‘engagement’. Although these broad types of activities are linked and complement each other, there is a distinction to be made:

- Participation is where people take part in a study as participants. Examples of this include being recruited to a clinical trial, completing a questionnaire, or taking part in a focus group or interview as part of a research study.

- Engagement is where information and knowledge about research is provided and disseminated to the public. This can include science festivals open to the public with debates and discussions on research, an open day at a research centre where members of the public are invited to find out about research, raising awareness about research through mediums such as podcasts or social media, or dissemination of research findings to members of the public or research participants.
- Involvement refers to instances where members of the public or patients are actively involved in research projects and working with individuals or organisations conducting research.

Involvement of knowledge users is the focus of this discussion. *Involve*, the UK's largest public participation charity, explains public involvement as research being carried out 'with' or 'by' members of the public, rather than 'to', 'about' or 'for' them. As we touched on earlier, the term 'public' is wide ranging and in the context of PPI includes patients, potential patients, carers and people who use health and care services, as well as people from organisations that represent people who use these services. Examples of PPI include:

- Serving as joint grant holders or co-applicants on a research project
- Identifying research priorities
- Membership of a project advisory or steering group
- Development of participant information sheets or other research materials
- Undertaking interviews with research participants
- Data analysis
- Preparing the research report and research publications

1.7.1 Why Prioritise Patient and Public Involvement?

At a fundamental level, it can be argued that PPI aligns with basic ethical principles and supports the notions of citizenship, public accountability and transparency. Patients and the public can also bring different perspectives that can complement so called 'expert' knowledge which can help improve the quality and relevance of research. Whilst all of us are actual, former, or indeed potential users of healthcare and nursing services, there is an important distinction to be made between the perspectives of the public and the perspectives of those of us who have a professional role in

nursing and research. We must not assume we know more than others and should recognise that other people will have expert knowledge and skills that will help our research project. Even when a researcher is an expert in their field, their knowledge and experience will be different to someone using a service or someone with lived experience of a health condition. No matter what the research may be, patients and the public can offer unique, invaluable insights and their advice in designing, implementing, and evaluating research can make studies more effective and more credible.

A research paper published by Rix et al. (2021) demonstrates how involving patients and members of the public in the design and conduct of a research study can make the research more person-centred. The research team aimed to explore ways of co-designing a study entitled 'Biomechanical Effects of Manual Therapy – A Feasibility Study' using usability testing (a physical walkthrough). Patient and public volunteers who had experienced low back pain were sought and invited to participate in usability testing of the proposed study method. In addition, their perspectives on recruitment strategies, continuity of participant care, and dissemination of results were explored. The feedback from the volunteers was considered by the research team and amendments to the original study method were revised accordingly to incorporate additional recruitment strategies, reduction in study time burden, use of a quieter location for completion of study paperwork, continuity of participant care after the study, and methods of dissemination to study participants.

Another case study of PPI collaboration, which was characterised by an ongoing partnership between researchers and members of the public and patients, is the Blueprint study (Blueprint Writing Collective 2022), which aimed to develop a 'model' of effective service design for children and young people with common mental health problems. To ensure Blueprint's findings were rooted in lived experience and informed by different perspectives, six young adults with lived experience of mental health issues were recruited, trained, and employed as co-researchers to work alongside academic researchers, which the research team considered invaluable to the outcomes of the project. The key to this approach is that decisions made about the research are genuinely shared. This could include activities such as developing the research grant application, being a member of a research study advisory group, or collaborating with researchers to

disseminate research findings. Using this approach to PPI, the skills and perspectives of patients, members of the public and researchers can complement each other. When adopting a collaborative approach to PPI, researchers need to be flexible and willing to share control of the research. Specific benefits to collaboration include helping to ensure that the research remains focused and relevant, and that the research is ethical. Additional benefits can include support with recruitment and informed consent. However, there are also potential challenges as collaboration can be time consuming and involve additional costs and researchers and PPI representatives may also require training or support.

PPI in research can also take the form of user-controlled, or user-led, research. This is where research projects are actively controlled, directed, and managed by service users (patients and the public), or service user organisations and they can decide on questions to be looked at, the aims of the research, the planning, design, and conduct of the research, as well as the writing up and dissemination of the research findings. There are several reasons user-led research is important for patients and the public, including a commitment to improving the lives of the community of service users, frustration with traditional research and services, which exclude the perspectives of patients and the public, and frustration with mainstream research in failing to capture the needs of service users, or to research things that service users feel are important. Some of the benefits of user-led research include a strong commitment to make change in line with what service users want, as well as an emphasis on supporting more equal research relationships and making involvement a more positive experience for participants. Some of the challenges of user-led research that have been documented in the literature include the continued dominance of medicalised and clinical research which restricts broader perspectives or non-medicalised approaches to research. Accessing funds has also been cited as problematic in user-led research. An example of user-led research is the Alzheimer's Society research network of volunteers who play an integral role in the organisational research programme, including:

- Setting research priorities
- Prioritising and reviewing grant applications

- Taking part in grant selection panels
- Monitoring ongoing funded projects

For more information see: www.alzheimers.org.uk/research-network-news/our-research-network-volunteers-having-impact-internationally

1.7.2 Benefits for Patients and Public Involved in Research

A wide range of benefits have been reported in the literature for those people who have taken part in research as part of a PPI initiative. This includes the opportunity to share experiential knowledge and having a 'voice' to influence processes that affect people's lives (including their own). It can also increase knowledge and support people in developing new skills. PPI is also seen as an altruistic act – allowing people to give something back. There are also potential therapeutic benefits, including developing new insights into one's own condition and experiences, as well as raised self-esteem and a sense of empowerment. Being involved can also help people to develop their confidence in encounters with healthcare professionals and support them to become more questioning. PPI can also provide relief from social isolation and loneliness and allow people to develop new friendships, connections and social networks.

However, people have also reported negative aspects of PPI in research projects. Physical issues can create barriers such as a lack of accessibility and illness, and there can sometimes be a lack of support and guidance for people who are new to PPI. This can be related to potentially confusing and complex new environments, with PPI representatives not knowing how things 'work'. In this respect, involvement can sometimes appear to be organised to suit agencies, rather than users and this can cause anxiety and feelings of exclusion and isolation for patient and public representatives. This can be further exacerbated by poor or ineffective relationships with research staff, with the potential to exploit the good will of patient and public representatives, who may not know if their contributions are valued. Family commitments and carer responsibilities can also impact people's level of involvement and financial issues can potentially be problematic. There can also be communication challenges, such as the language used by the 'professionals', which may not be the same as that used by patient and public representatives and signing and simultaneous translation may not be available. It is therefore essential that researchers proactively consider these issues so that barriers to meaningful PPI are overcome.

1.8 Summary

We've reached the end of this first chapter, which has served as an introduction to nursing research, so we will now summarise the key concepts and main points of learning, which you can take forward into the next chapters. *Research* systematically investigates ideas to increase knowledge and devise new interventions and ways of working by establishing or confirming facts, reaffirming previous knowledge, solving problems, and supporting or developing new theories. In nursing, we can then use this new knowledge to inform our practice, by providing the evidence to support evidence-based nursing practice. *Study design* is concerned with how the research question can be investigated, the plan for collecting and analysing the data and decisions about the methodological approach. *Methodology* is the overall approach to the research (qualitative, quantitative) and provides the theoretical underpinning to undertaking a piece of research and for understanding which methods to apply to a specific research question. *Methods* are the ways in which data are collected or generated (not to be confused with the methodology). It is important to remember that *methodological congruence* is key: the research question, aims, objectives, methodology, and methods must all align. *PPI* can significantly strengthen a research study.

