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# Health system readiness for radioligand therapy in the UK

## Health information

Working paper

September 2021

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## Contents

|  |    |
|--|----|
| About this working paper .....                                   | 3  |
| What is health information? .....                                | 5  |
| What does good health information look like? .....               | 5  |
| 1 Research and data .....  | 7  |
| 1.1 Clinical trial data .....                                    | 7  |
| 1.2 Clinical, registry and audit data .....                      | 8  |
| 1.2.1 Clinical, registry and audit data on NENs .....            | 10 |
| 1.2.2 Clinical, registry and audit data on lymphoma .....        | 11 |
| 1.2.3 Clinical, registry and audit data on prostate cancer ..... | 12 |
| 1.3 Economic data.....   | 13 |
| 1.4 Real-world data .....  | 13 |
| 1.5 Patient-reported outcomes data .....                         | 14 |
| Conclusion .....   | 16 |
| References .....   | 17 |

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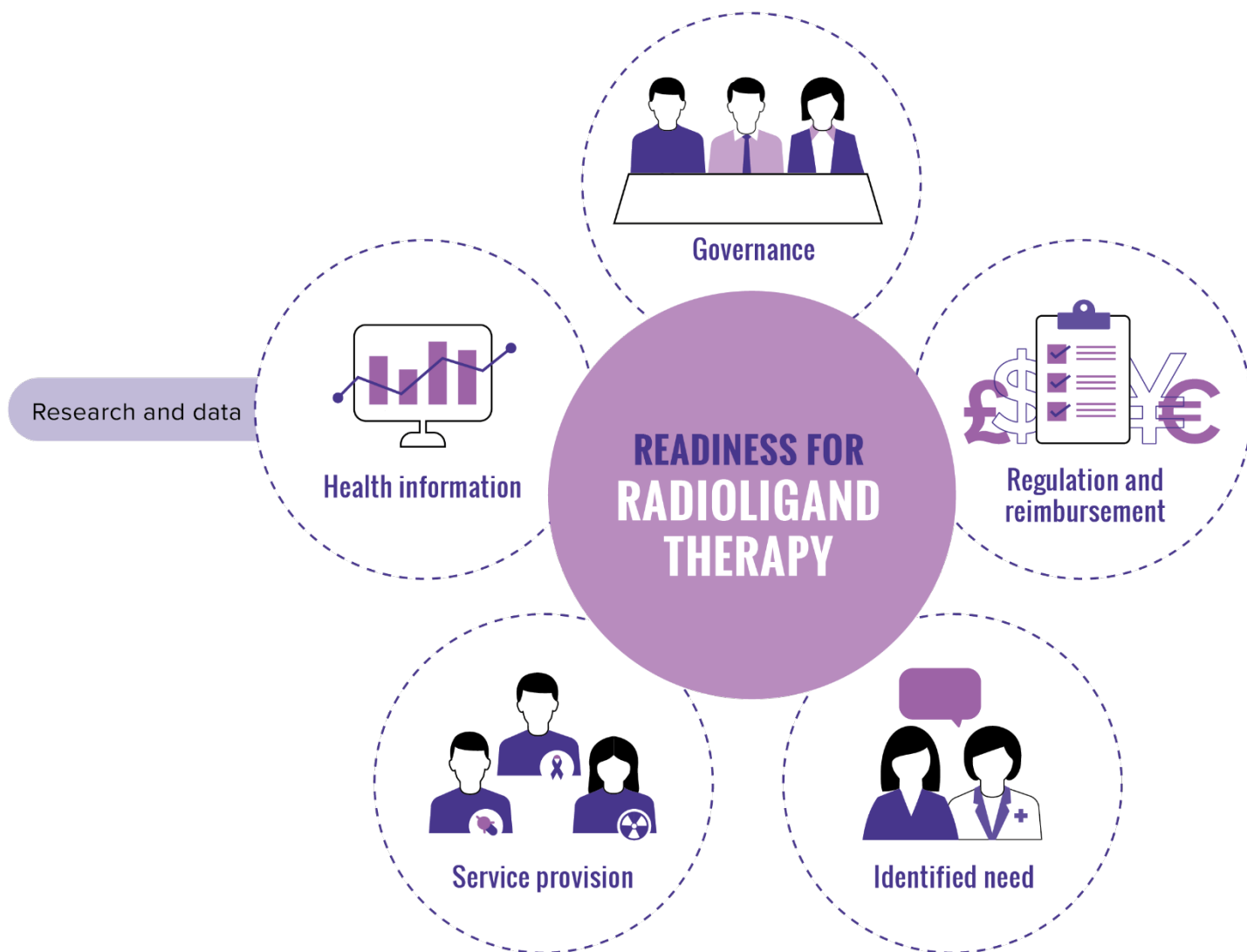
## About this working paper

**This working paper is part of a broader piece of work aiming to define what is needed to establish system-level readiness for radioligand therapy in the UK.** It explores current integration and future readiness for the approach as it relates to health information, one of the five domains of the Radioligand Therapy Readiness Assessment Framework (*Figure 1*). The working paper provides answers to questions from the framework, with key findings from relevant subdomains outlined in a summary assessment at the start of each section. Throughout this paper, we focus on the situation in neuroendocrine neoplasms, lymphoma and prostate cancer in England, though we also include examples from across the devolved nations. Many of the findings in this paper may be applicable across the UK and in other areas of cancer care.

- This working paper is supported by other documents on health system readiness for radioligand therapy in the UK. For more details, please visit:  
[www.radioligandtherapy.com/framework/UK](http://www.radioligandtherapy.com/framework/UK)

**This working paper uses the term radioligand therapy**, but there are various terms used for the approach, including: peptide-receptor radionuclide therapy (PRRT), systemic radiation therapy, targeted radionuclide therapy, targeted radiotherapy and molecular radiotherapy. When the ligand used is an antibody, the approach is known as radioimmunotherapy.

Figure 1. Domains of the Radioligand Therapy Readiness Assessment Framework



## What is health information?

**Health information is the foundation of decision-making across all areas of the health system.** It may be defined as the data that are collected, analysed and synthesised to support health-related decision-making. The NHS has recognised the value of high-quality information to support planning and commissioning of healthcare services, as well as to improve patient care and outcomes.<sup>1</sup> Health information is also essential for policy development and implementation, governance, regulation, financing, human resources planning, health education and training, and service delivery.

This working paper provides an overview of the availability and quality of clinical trials and registry data, economic data, real-world data and patient-reported outcomes data pertaining to radioligand therapy. It considers the effectiveness of current data collection approaches relevant to radioligand therapy to meet the needs of decision-makers, healthcare providers and patients.

## What does good health information look like?

**The form and format of data collection mechanisms influence the quality of data available and the feasibility of using the information gathered.** Health information should be collected in a way that enables data analysis and, ultimately, allows data to have an impact on future practices. To facilitate robust analysis, data must be complete; they cannot have extensive missing or inaccurate information. Data entry systems which are efficiently structured with the end user in mind are more likely to produce complete outputs.<sup>2</sup> <sup>3</sup> Good data collection also requires interoperability, which enables collation and comparison between data sources.<sup>3,4</sup> Connecting data sets is an important component of research which helps us gain a greater understanding of the comparative value of health interventions. Interoperability requires consensus on and consistency in data structure and standards.<sup>4</sup> Finally, it is necessary that data collection mechanisms are flexible, and can be easily updated to answer new and unforeseen research questions.

**Effective integration of radioligand therapy requires the systematic collection and timely analysis of robust data across the NHS.** Incorporation of radioligand therapy into an existing national database, or the creation of a new radioligand therapy registry, would enable a more accurate understanding of the uses and potential benefits of the approach. Establishing, maintaining and analysing data requires funding and workforce capacity. With sufficient resources in place, the outputs can be analysed to gain an understanding of cancer care across the UK, and to improve cancer care and healthcare more generally.<sup>5-7</sup>

# 1 Research and data

## Summary assessment

| Indicator   | Assessment  |
|---|---|
| Is there sufficient data collection on radioligand therapy in the UK to guide future planning and practice? | <p>Data collection practices in the UK do not adequately capture how radioligand therapy is used in clinical practice. There is no multi-indication radioligand therapy-specific data collection mechanism, and existing disease-specific health information sources (on neuroendocrine neoplasms, lymphoma and prostate cancer) poorly capture data on the use of therapies, including approved radioligand therapy where relevant.</p> <p>There are also limited economic, real-world and patient-reported outcomes data collected.</p> |

### 1.1 Clinical trial data

More clinical trial data are needed to fully understand which groups of patients will benefit most from radioligand therapy and at which stage of cancer. Various trials are underway in the UK:

- Clinical trial data for radioligand therapy in neuroendocrine neoplasms (NENs) are growing. Data from the NETTER-1 trial have built an important foundation for clinical knowledge,<sup>8 9</sup> and additional trials are ongoing, such as the NETTER-2 and COMPETE trials.<sup>10 11</sup> Brexit is likely to impact the UK's involvement in European clinical research, which may be detrimental to research in NENs in some areas (*Box 1*).
- There is substantive clinical trial data for radioligand therapy in lymphoma. Data from earlier therapies have provided evidence of the potential value of radioligand therapy in lymphoma.<sup>12-15</sup> Clinical trials exploring the use of novel radioligand therapies in these indications are ongoing, such as the Phase 1 and 2 LYMRIT-37 trials.<sup>16-18</sup>
- Phase 3 clinical trials including UK patients, such as the VISION trial, are underway in advanced prostate cancer.<sup>19</sup> Clinical trials are also underway internationally, although they do not include UK sites.<sup>20</sup> Evidence from these trials will be critical for

approval of radioligand therapy in this area by the Medicines and Healthcare products Regulatory Agency (MHRA) and to secure positive guidance from the National Institute for Health and Care Excellence (NICE). Early findings from the VISION trial suggest that radioligand therapy improves overall survival and radiographic progression-free survival.<sup>21</sup>

### Box 1. Impact of Brexit on data collection in neuroendocrine neoplasms

For rare cancers like NENs, involvement in European and international trials is vital. Without pan-European cooperation in rare diseases, data collection and analysis in the UK will pose additional challenges.<sup>3</sup>

Cancer research organisations and charities have emphasised the uncertainty that Brexit poses to collaboration on European clinical trials and research projects.<sup>22</sup> This may impact patients' ability to participate in some EU research projects and trials, such as European Reference Networks for Rare Cancers (EURACAN).<sup>23 24</sup> Fortunately, some collaborations will continue. For example various non-EU countries participate in the European Neuroendocrine Tumour Society (ENETS) Registry, and it is expected that the UK will continue to participate in this registry.<sup>23 24</sup>

## 1.2 Clinical, registry and audit data

**Data for radioligand therapy are not systematically collected and outputs are highly fragmented.** Data collection is currently managed by a number of organisations, from nationally devolved health bodies such as Public Health England and Public Health Scotland, to professional groups, hospitals and charities.<sup>25-28</sup> Charities collect data primarily for advocacy purposes, while NHS trusts collect disease- and therapy-specific information with a view to service improvement. Every year, the Internal Dosimetry Users Group collects data on the use of radiotherapy, including radioligand therapy, to assess its usage across the UK.<sup>29</sup> Publications reference specific cancers but do not include detailed clinical characteristics or information on treatment outcomes. Moreover, these clinical data are submitted voluntarily, so may not fully reflect all experiences with the approach. Inconsistent

data collection across numerous institutions makes it difficult to assess the actual use of radioligand therapy across the UK.

**Incorporating radioligand therapy into existing data collection mechanisms may be the most efficient way to increase the amount and quality of information about the approach.** There are a number of national cancer-, treatment- and disease-specific registries and audits across the UK.<sup>27 30-32</sup> These comprehensively cover many cancer therapies and have good interoperability.<sup>33-35</sup> For example, England's National Radiotherapy Data Set has collected consistent and comparable data on radiotherapy services since 2009 and can be linked to other data sets (*Real-world example 1*). Data collection for radioligand therapy could be integrated into an established national data set such as this; alternatively, a separate national data set for radioligand therapy could be created. Either would offer healthcare practitioners a more comprehensive understanding of the approach relative to other treatment modalities.

### **Real-world example 1. National Radiotherapy Data Set for England**

England's National Radiotherapy Data Set (RTDS) was established in 2009 to collect comparable and consistent data across all radiotherapy services.<sup>32</sup> All NHS trusts that provide radiotherapy must collect a standard data set on a monthly basis.<sup>36</sup> The RTDS builds a picture of current service provision and changes over time, with a view to informing future planning, provision and commissioning of radiotherapy services. It is also used to support research on new treatments and delivery techniques.<sup>37</sup> RTDS was created through a collaboration of cancer networks, commissioners and radiotherapy service managers.

Public Health England's leadership of the RTDS has enabled the integration of radiotherapy data into other national cancer data sets.<sup>36</sup> This allows deeper analyses of site-specific outcomes by patient and treatment variables, and increases understanding of the role of radiotherapy in improving outcomes compared with other treatment modalities.<sup>32</sup> For example, combining data from the RTDS and National Cancer Data Repository has allowed for an in-depth understanding of inequalities in access to radiotherapy for the treatment of lymphoma.<sup>34</sup>

## 1.2.1 Clinical, registry and audit data on NENs

**Greater leadership and support are required to help make NENs data collection more comprehensive and consistent.** There is no national disease-specific registry or audit on NENs. Although data on NENs have been recorded through the English Cancer Registry since 2013,<sup>38</sup> these have been minimal in comparison with more common cancers. Neuroendocrine Cancer UK tries to collect additional data on the delivery of NENs services in NHS trusts across the UK and analyses this data to understand the gaps in service provision;<sup>36</sup> however, these data are not collected systematically due to a lack of adequate resources and funding.<sup>39 40</sup> It may be more difficult to establish national registries for rare cancers such as NENs because of the limited number of people living with the condition, but cross-border collaboration can help. At a European level, the European Neuroendocrine Tumor Society (ENETS) Centers of Excellence are required to keep an on-site database and registry.<sup>40</sup> Sites can contribute these data to a European-wide registry, but privacy and data protection requirements may limit the UK's involvement in this initiative.<sup>40</sup>

**Nationally coordinated data collection on people receiving radioligand therapy for NENs is newly emerging.** The British Nuclear Medicine Society (BNMS) has launched a voluntary national radioligand therapy registry for NENs (*Real-world example 2*). The registry has the potential to become a valuable resource to understand how radioligand therapy is currently used in NENs, and its efficacy and costs. If linked to registries that collect data on other NENs treatments, the BNMS registry could also be used to understand the comparative value of radioligand therapy. At present, the BNMS registry is not linked to any other data sets.

### Real-world example 2. Radioligand therapy registry in NENs

The BNMS has collaborated with the University of Surrey to develop a national registry for radioligand therapy<sup>41 42</sup> that would collect robust data on people receiving radioligand therapy for NENs.<sup>43</sup>

The registry includes information on patient demographics, diagnosis, previous treatments, radioligand therapy treatment cycle, side effects and outcomes.<sup>26 41</sup> Data input takes approximately 15 minutes per patient, and can be completed during patient consultation. Each NHS trust may nominate a person to input data, which may include NENs nurses, nuclear medicine physicists or dosimetrists.<sup>41</sup> The trust owns all data that it uploads, but all data are anonymised and made available to all stakeholders that contribute to the registry.<sup>41</sup>

The registry has been made available on the BNMS website.<sup>26</sup> It could be modified to incorporate future applications of radioligand therapy, for example in prostate cancer and lymphoma.<sup>41</sup>

## 1.2.2 Clinical, registry and audit data on lymphoma

**Data are collected on therapies for lymphoma, but this does not include radioligand therapy.** The Cancer Outcomes and Services Dataset (COSD) is a national data set which includes comprehensive data on diagnosis and specific treatments, such as chemotherapy and radiotherapy, for many cancers, including lymphoma (*Box 2*).<sup>27 44</sup> There is no indication that radioligand therapy data are included in this data set, although the approach has been used in lymphoma in the past decade.<sup>29</sup> Therefore, to ensure that the COSD maintains relevance in the future, it should be expanded to include emerging cancer therapies such as radioligand therapy.

### Box 2. The Cancer Outcomes and Services Dataset

The Cancer Outcomes and Services Dataset (COSD) is the primary cancer outcomes data set in the UK and includes data from the Systemic Anti-Cancer Therapy (SACT) data set.<sup>27 45</sup> The COSD aims to collect comprehensive and standardised data on cancer diagnosis, treatment and outcomes.<sup>27</sup> As such, it contains a variety of mandatory fields, and healthcare providers must submit information from their institutions to the COSD within three months of data collection.<sup>27</sup>

Data from the COSD are published annually and feed into the wider National Cancer Registration and Analysis Service, which is used to support healthcare and research across England.<sup>27 46</sup>

### 1.2.3 Clinical, registry and audit data on prostate cancer

**Data collection for prostate cancer is established but will require expansion to integrate radioligand therapy over time.** There are a number of prostate cancer registries and audits that evaluate data on the use of existing therapies:

- The UK National Prostate Cancer Audit (NPCA) collects a comprehensive data set, including data on therapeutic approaches and treatment allocation, with specific measures for people with metastatic disease.<sup>30</sup> New therapies are considered for inclusion in the audit if data are collected by other, larger data sources, such as the National Radiotherapy Data Set.
- The COSD includes data specific to prostate cancer.<sup>44</sup>

As data on therapeutic options are already collected in the NPCA and COSD, integrating data collection on new therapies seems feasible. Such efforts will require decision-makers to commit funding and resources.

### 1.3 Economic data

**There are limited economic data on radioligand therapy.** In the short and long term, it will be vital for healthcare decision-makers to have access to economic data on therapies, such as radioligand therapy, to support their understanding of budget impact and cost-effectiveness.<sup>47 48</sup> It is especially valuable to have economic analyses that compare radioligand therapy to different therapeutic approaches, to improve understanding of the relative value of the approach. These data are vital to guide health technology assessments. Specifically, a lack of economic data contributed to the Scottish Medicines Consortium's decision not to recommend reimbursement of radioligand therapy for the treatment of lymphoma.<sup>49</sup> New UK-specific cost-effectiveness data on radioligand therapy are emerging, with a recent study indicating that this therapy may be cost-effective for NENs in Scotland.<sup>50</sup> However, further economic data on radioligand therapy will need to be gathered in real-world studies to ensure that the potential value of the approach is accurately understood. These data will also help the UK plan for funding of the approach from a health system perspective.<sup>51</sup>

- For more information about the reimbursement of radioligand therapy, read the working paper on [regulation and reimbursement](#).

### 1.4 Real-world data

**Real-world data on radioligand therapy are lacking, both in the UK and globally.**<sup>47 52</sup> Although clinical trials in radioligand therapy are ongoing,<sup>16 19 20</sup> more real-world data that reflect long-term outcomes and patient experiences in clinical practice will also be critical for improving the evidence base. Evidence from real-world data can support healthcare decision-makers in better understanding the effectiveness, safety and costs associated with radioligand therapy when given to a broad population outside of the experimental context of clinical trials. This evidence can support its incorporation into clinical practice and guidelines and can, in turn, support healthcare professionals in their treatment decision-making processes. Initiatives are underway to develop a Europe-wide data collection mechanism – European Health Data and Evidence Network (EHDEN) – that seeks to build the evidence base for real-world data that supports clinical decision making (*Real-world example 3*). Efforts such as this initiative could help to build the knowledge base for long-term outcomes

of radioligand therapy in a patient-centred way. Of note, the UK will remain involved in EHDEN following Brexit.<sup>53</sup>

### Real-world example 3. European Health Data and Evidence Network

To address the challenges in generating evidence from real-world data at scale, the multi-stakeholder European Health Data and Evidence Network (EHDEN) was established in 2018. EHDEN is part of the Big Data for Better Outcomes Programme, funded by the European Commission's Innovative Medicines Initiative.<sup>54</sup> It brings together 22 partners from universities, patient organisations, small businesses and the pharmaceutical industry to create ownership of real-world healthcare data, with a focus on personalised medicine.<sup>55</sup> Its database currently has over 200 million patient records.<sup>56</sup>

EHDEN has many programmes, including the following:

- A federated network for data partners that facilitates collaboration on new research methodologies and education.<sup>57</sup> This includes partner GP networks, hospitals and regional databases. Of the 61 research partners, 12 are based in the UK.
- Training, certification and funding to standardise health data to the Observational Medical Outcomes Partnership common data model.<sup>58</sup> This transforms data from different databases into a common format, facilitating systematic analysis.
- An online training academy that provides development opportunities on real-world data for EHDEN partners.

## 1.5 Patient-reported outcomes data

**There is no systematic data collection of patient-reported outcomes from people undergoing radioligand therapy.** In 2020, Neuroendocrine Cancer UK and the UK and Ireland Neuroendocrine Tumour Society (UKINETs) developed a mobile app to collect patient-reported outcomes data for people with NENs who are receiving different therapies, including radioligand therapy.<sup>59</sup> This initiative aims to collect data from approximately

2,000 people with NENs and may improve understanding of the patient experience of different therapies.<sup>59</sup> It is a valuable step towards understanding the potential benefits of radioligand therapy; however, data collection is not systematic, so may not be fully representative of people's experiences of care. Beyond this app, collection of patient-reported outcomes data for radioligand therapy is limited. As existing national registries do not include data on radioligand therapy, patient-reported outcomes associated with this approach are not measured nationally.<sup>60</sup> The Blood Cancer Alliance collects comprehensive patient experience data for lymphoma, and the National Prostate Cancer Audit includes patient-reported outcomes data for prostate cancer; however, neither of these include information about radioligand therapy.<sup>7 61</sup>

**Patient-reported outcomes data are important to guide our understanding of the wider impact of radioligand therapy on patients' quality of life.** Data suggest that radioligand therapy may have a positive impact on quality of life,<sup>62</sup> but more information is needed to guide clinical care. There is a strong emphasis on this type of data collection more generally within cancer care. For example, the National Cancer Patient Experience Survey is an annual survey that collects patient-reported outcomes.<sup>63</sup> Its results can be linked to the National Cancer Registration and Analysis Service data set to explore trends in patient experiences based on different cancer types or therapies used.<sup>33 64</sup> However, the component data sets, such as the COSD, would need to be expanded to include radioligand therapy before the National Cancer Patient Experience Survey can be used in the context of this treatment.

## Conclusion

**There are several important gaps in clinical data collection on radioligand therapy in the UK.** Most notably, there are no specific data collection mechanisms for monitoring the therapy's use. From a disease-specific perspective, although national registries include information on prostate cancer and lymphoma treatments, they do not yet include appropriate data collection for radioligand therapy. Given that radioligand therapy does not currently have market authorisation in prostate cancer, its absence from registries in this indication is understandable. Systematic data collection on NENs at a national level is poor, though the continued participation in the ENETS Registry and launch of the BNMS radioligand therapy registry in NENs are promising. Integration of future radioligand therapy in the newly developed NENs registry or other existing cancer and therapy registries is an essential step for ensuring successful integration of the approach into wider clinical cancer care.

**The lack of real-world, economic and patient-reported outcomes data limits understanding of the potential value of radioligand therapy.** Information about the advantages of radioligand therapy from economic, real-world and patient perspectives can help ensure that the approach is considered and available in all appropriate situations – for example, on the NHS – and that its impact on quality of life is clearly understood. Inclusion of radioligand therapy in existing data collection mechanisms such as EHDEN and the National Cancer Patient Experience Survey would generate data on real-world and patient experiences, respectively. Data on the comparative economic value of radioligand therapy may need to be generated through new clinical trials or real-world studies.

**Future readiness for radioligand therapy will require strong information systems to be in place.** This will involve making current data collection practices more efficient and ensuring that existing registries, audits and information systems are complete and have good interoperability. Additionally, collaborative working with research partners across the NHS will be important to ensure that radioligand therapy is incorporated into existing data collection mechanisms and research. Sufficient staff and funding will be required to facilitate improvements in health information for radioligand therapy. Efforts to improve data collection will aim to have wide-ranging impact; by improving health information for NENs, lymphoma, prostate cancer and any other future indications, we may also improve the understanding of how cancer care is provided at a system level.

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