






# Neuroendocrine neoplasms: Consensus on a patient care pathway

Jessica Hooper<sup>1</sup>  | Nikie Jervis<sup>2</sup> | Lucy Morgan<sup>1</sup>  | Vivienne Beckett<sup>3</sup> |  
 Philippa Hand<sup>4</sup> | Kate Higgs<sup>5</sup> | Alia Munir<sup>6</sup> | Jenny Prinn<sup>7</sup> |  
 D Mark Pritchard<sup>8</sup>  | Debashis Sarker<sup>9</sup>  | Raj Srirajakanthan<sup>10</sup>  |  
 Catherine Bouvier Ellis<sup>2</sup>

<sup>1</sup>The Health Policy Partnership, London, UK

<sup>2</sup>Neuroendocrine Cancer UK, Leamington Spa, UK

<sup>3</sup>Advanced Accelerators Applications (UK & Ireland) Ltd, a Novartis Company, London, UK

<sup>4</sup>London North West University Healthcare NHS Trust, London, UK

<sup>5</sup>Ipsen UK, Slough, UK

<sup>6</sup>Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Teaching Hospitals European Neuroendocrine Tumor Society Center of Excellence, Sheffield, UK

<sup>7</sup>Canterbury, UK

<sup>8</sup>University of Liverpool and Liverpool University Hospitals NHS Foundation Trust, Liverpool Regional NET Service (European Neuroendocrine Tumor Society Center of Excellence), Liverpool, UK

<sup>9</sup>Guy's, St Thomas' and King's College Hospitals, King's Health Partners NET Centre (European Neuroendocrine Tumor Society Center of Excellence), London, UK

<sup>10</sup>King's College Hospital NHS Foundation Trust, King's Health Partners NET Centre (European Neuroendocrine Tumor Society Center of Excellence), London, UK

## Correspondence

Jessica Hooper, The Health Policy Partnership, 68–69 St Martin's Lane, London, WC2N 4JS, UK.

Email: [jessica.hooper@hpolicy.com](mailto:jessica.hooper@hpolicy.com)

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## Abstract

People with neuroendocrine neoplasms (NENs) face a multitude of challenges, including delayed diagnosis, low awareness of the cancer among healthcare professionals and limited access to multidisciplinary care and expert centres. We have developed the first patient care pathway for people living with NENs in England to guide disease management and help overcome these barriers. The pathway was developed in two phases. First, a pragmatic review of the literature was conducted, which was used to develop a draft patient care pathway. Second, the draft pathway was then updated following semi-structured interviews with carefully selected expert stakeholders. After each phase, the pathway was discussed among a multidisciplinary, expert advisory group (which comprised the authors and the Deputy Chief Operating Officer, West Suffolk NHS Foundation Trust), who reached a consensus on the ideal care pathway. This article presents the outputs of this research. The pathway identified key barriers to care and highlighted how these may be addressed, with many of the findings relevant to the rest of the UK and international audiences. NENs are increasing in incidence and prevalence in England, compounding pre-existing inequities in diagnosis and disease management. Effective integration of this pathway within NHS England will help achieve optimal, equitable care provision for all people with NENs, and should be feasible within the existing expert multidisciplinary teams across the country.

## KEYWORDS

cancer, inequity, neuroendocrine neoplasm, pathway

## 1 | INTRODUCTION

Neuroendocrine neoplasms (NENs) are a diverse group of cancers that are increasing in incidence globally.<sup>1</sup> NENs can be subdivided into well-differentiated neuroendocrine tumours (NETs) and poorly differentiated, high-grade neuroendocrine carcinomas (NECs).<sup>2</sup> The classification of NETs and NECs is underpinned by genetic, clinical, epidemiologic, histologic and prognostic differences.<sup>2</sup>

Globally, the incidence of NENs is rising.<sup>3</sup> In 2018, the incidence of NENs in England was 8.61 per 100,000 people, a marked increase from 2.35 per 100,000 in 1995.<sup>1</sup> Prevalence has also risen; NENs have become the 10th most prevalent cancer in England.<sup>1</sup> However, NENs have diverse presentations, and limited awareness of NENs makes diagnosis and management complex.<sup>4</sup> The majority of people receive an NENs diagnosis at an advanced stage when care is expensive and may not be as effective.<sup>5-7</sup>

To reduce the burden on the health system and improve the quality of life of people with NENs, we need to address persistent challenges, delays and inequities in the diagnosis and management of the disease. Such targets align with the ambitions of the UK Rare Diseases Framework,<sup>8</sup> the NHS Long Term Plan<sup>9</sup> and the forthcoming Major Conditions Strategy.<sup>10</sup>

Care pathways provide a rubric for mutual decision-making and care for a given group of people.<sup>11</sup> They aim to enhance the quality of organisation of care and increase cost-effectiveness by improving the consistency of care, streamlining health system processes and optimising resource distribution.<sup>11,12</sup> The cost efficiency of implementing care pathways for various disease areas and patient groups has been demonstrated,<sup>13-18</sup> such as through an integrated care pathway for rehabilitation of people with hip fractures in Sweden.<sup>14</sup> The introduction of clinical pathways has also been associated with reduced waiting times<sup>19</sup>; this, in turn, has been linked to improved patient satisfaction and quality of care.<sup>20</sup>

Expert stakeholders have acknowledged the value of national care pathways for improving the care and survival of people with NENs worldwide.<sup>21</sup> National care pathways could enhance knowledge of NENs among healthcare professionals and ensure effective diagnostics and access to appropriate treatments.<sup>21</sup> However, there is no complete care pathway for NENs in England.

Against this background, Neuroendocrine Cancer UK (NCUK), The Health Policy Partnership and a variety of expert stakeholders have developed an ideal care pathway for people living with NENs in England.<sup>22</sup> Implementation of the patient care pathway for neuroendocrine cancer is essential for optimal, long-term and multidisciplinary care for people with NENs across the country, from point of suspicion to follow-up care.<sup>3</sup> This article outlines

- the process undertaken to develop this standardised care pathway
- the key barriers to care that have been identified along the pathway and how these might be addressed
- considerations to ensure cost-efficient implementation of the care pathway
- the policy recommendations to support effective pathway implementation into NHS England practice.

## 2 | METHODS

Multiple methods of data collection were used alongside consensus-building exercises to inform the development of the patient care pathway (see Figure 1).

### 2.1 | Review of the literature

CBE and NJ gathered initial evidence about the experience of people with NENs and the need for a patient care pathway via snowball sampling. We reviewed this evidence and identified key gaps in our understanding of the ideal patient care pathway. To compile all available literature relevant to the development of the patient care pathway, we conducted a top-up, pragmatic literature review with a streamlined methodology.<sup>23</sup>

To inform the development of this publication, an additional top-up review of literature on the cost-effectiveness of implementing the patient care pathway for neuroendocrine cancer was conducted.

#### 2.1.1 | Search strategy and inclusion/exclusion criteria

We conducted a review of peer-reviewed and grey literature in May 2022. We searched three electronic databases (PubMed, Google and

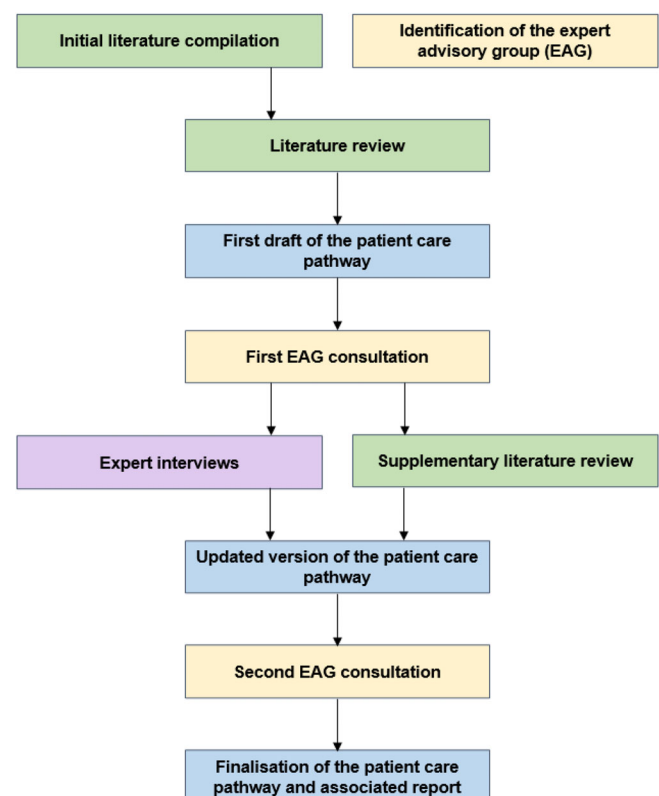


FIGURE 1 Overview of methodology.

**TABLE 1** Terms used for the literature search.

Concept	Search terms
Neuroendocrine neoplasms (NENs)	Neuroendocrine cancer OR neuroendocrine tumour OR neuroendocrine tumor OR neuroendocrine neoplasm OR neuroendocrine carcinoma
Care pathway	Care pathway OR pathway OR regimen
Diagnosis	Diagnosis OR diagnostic method OR point of suspicion
Treatment	Treatment OR management OR therapy OR intervention
Multidisciplinary team (MDT)	Multidisciplinary team OR healthcare professional OR oncologist OR general practitioner OR cancer specialist nurse
NHS England (NHSE)	NHS England OR England OR NHSE
Search string combinations	
NENs AND care pathway	
NENs AND diagnosis	
NENs AND treatment	
NENs AND multidisciplinary team	
NENs AND NHS England	
NENs AND care pathway AND multidisciplinary team	
NENs AND care pathway AND NHS England	
NENs AND diagnosis AND treatment	
NENs AND multidisciplinary team AND NHS England	

Google Scholar) using a pre-defined search strategy (see Table 1). We also reviewed the reference lists of relevant publications to identify any supplementary reading and reviewed materials highlighted by the expert advisory group (EAG).

We reviewed all material according to pre-defined inclusion and exclusion criteria. Our inclusion criteria were (a) English language publications, (b) published between January 2017 and May 2022, (c) relevant research from Europe and (d) commentaries, editorials, empirical research papers, project reports and guidelines, which referenced the phase(s) of an NENs patient's journey. Our exclusion criteria were (a) articles that contained solely clinical information and (b) articles where the full text was not available.

These criteria were decided by our intention to develop a patient care pathway specific to the English context, informed by European practice, and spanning from the point of suspicion of NENs to follow-up care and ongoing treatment.

#### *Additional top-up review of literature on cost-effectiveness*

We conducted a review of peer-reviewed and grey literature in November 2023. We searched three electronic databases (PubMed, Google and Google Scholar) using the following search string combinations, including concepts from Table 1 (bold):

- **NENs** AND [cost-effective OR cost-effectiveness analysis]

- **NENs AND care pathway** AND [cost-effective OR cost-effectiveness analysis]
- **NENs AND diagnosis** AND [cost-effective OR cost-effectiveness analysis]
- **NENs AND treatment** AND [cost-effective OR cost-effectiveness analysis]
- **NENs AND diagnosis AND treatment** AND [cost-effective OR cost-effectiveness analysis]

We also reviewed the reference list of relevant publications to identify any supplementary reading and reviewed materials highlighted by the EAG.

We reviewed all material according to pre-defined inclusion and exclusion criteria. Our inclusion criteria were (a) English language publications, (b) published between January 2017 and November 2023, (c) relevant research from regions outside of the UK and (d) commentaries, editorials, empirical research papers, project reports and guidelines, which referenced the cost effectiveness of NEN care interventions. Our exclusion criteria were (a) articles that contained solely clinical information and (b) articles where the full text was not available.

These criteria were informed by our intention to explore the cost-benefit of implementing the patient care pathway for neuroendocrine cancer, the implications for policy development and the international relevance of the pathway.

### 2.1.2 | Literature review outcomes

Initial searches identified 1240 potentially relevant publications. We also completed a top-line review of recent publications from the European Neuroendocrine Tumor Society (ENETS), European Cancer Organisation, European Society for Medical Oncology, the UK and Ireland Neuroendocrine Tumour Society (UKINETS) and NHS England.

Following the review of the abstracts, organisations' websites and reference lists, 129 publications were selected for full-text screening and underwent detailed analysis (see Figure 2).

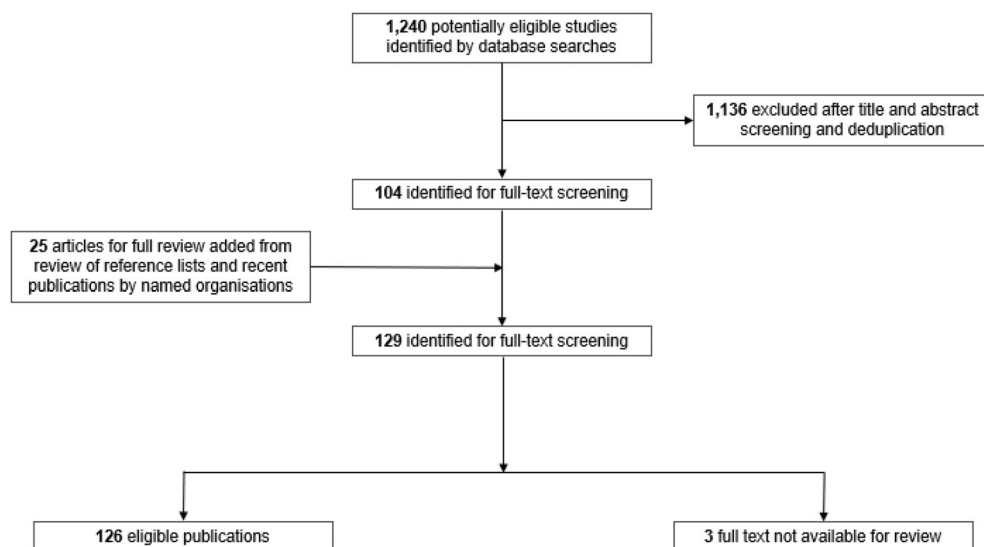
#### *Additional top-up review of literature on cost-effectiveness*

The additional review of literature on cost-effectiveness found 19 potentially relevant publications, with 17 identified for full-text screening.

Following the review of the abstracts and reference lists, 29 publications were identified as relevant, with a total of 46 publications therefore selected for full-text screening. After screening and detailed analysis, 33 eligible publications were confirmed.

## 2.2 | Expert advisory group

JH and LM analysed the stakeholder landscape in the UK via a review of leading publications authored by members of specialist centre



**FIGURE 2** The search and selection process for relevant publications.

multidisciplinary teams (MDTs) and professional societies, and via discussion with the patient advocacy and support organisation leads. Fourteen experts were shortlisted and approached for engagement in the project. These individuals included people with NENs, MDT clinicians, specialist cancer nurses, industry representatives and NHS England representatives.

Based on those with publicly available contact details, 10 individuals were invited to form the EAG for the project. Nine people accepted this invitation, with the remaining individuals agreeing to review the report.

Two meetings of all EAG members took place in June and October 2022 to discuss the structure of the patient care pathway and core barriers to care. A new member was invited to join after the first meeting based on EAG members' recommendations. In addition to the EAG meetings, members reviewed several drafts of the patient care pathway and associated report, and three members also participated in expert interviews. The EAG worked iteratively and collaboratively to ensure consensus on the direction and content of the final document.

## 2.3 | Expert interviews

To supplement the literature, we conducted eight semi-structured interviews with key individuals identified during stakeholder landscaping. We also garnered written feedback from six individuals. The outcome of the outreach process is detailed in Figure 3.

Experts were carefully selected to speak to gaps identified in the literature. The interviewees and report contributors had a variety of backgrounds—including people with NENs, academics, specialist cancer nurses, general practitioners (GPs) and NHS England representatives.

Interviews were designed to address the identified gaps in the literature, informed by EAG members' questions about the draft patient care pathway, and guided by discussion guides that were individually tailored.

## 2.4 | Analysis

The structure of the patient care pathway was informed by the NHS pledges, principles and values for care outlined in the NHS Constitution for England,<sup>24</sup> to ensure maximum impact and interoperability of the patient care pathway.

Data compiled from literature review, EAG consultation and expert interviews were categorised according to the phases of care outlined in the *Handbook to the NHS Constitution*.<sup>25</sup> Data in each phase were subsequently reviewed, and key themes were identified using the principles of thematic analysis.

## 3 | RESULTS

### 3.1 | Phases of the patient journey

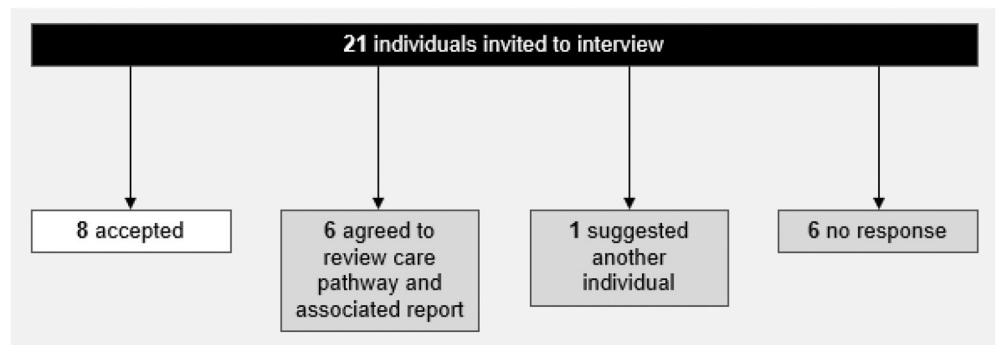
#### 3.1.1 | Point of suspicion

The point of suspicion marks a person's entry into a patient care pathway. Referrals of people with suspected cancer can be made from GP surgeries, emergency departments, hospitals and through NHS cancer screening programmes.<sup>26</sup> From there, people should follow the relevant designated cancer care pathway, such as the NHS England rapid diagnostic and assessment pathways for colorectal, lung, oesophago-gastric or prostate cancers,<sup>27–30</sup> the Oxford Suspected CANcer diagnostic pathway<sup>31</sup> or regional pathways for non-specific symptoms.<sup>32–34</sup>

#### *Barriers to care*

**Asymptomatic and diverse symptom presentation:** Many people are asymptomatic before being diagnosed with NENs. Where symptoms do occur, the most frequent are non-specific and may mimic those of more common conditions or experiences (e.g., irritable bowel syndrome, menopause).<sup>5,35–40</sup> These challenges often contribute to frequent misdiagnosis, inducing significant delays in an accurate

**FIGURE 3** Outcome of the outreach process for expert interviews.



diagnosis of up to 5 years or more.<sup>5</sup> Delayed diagnosis increases healthcare costs in a range of diseases.<sup>41-44</sup> This is likely to be a concern in NENs care too, as it involves utilising a large amount of resources even before diagnosis,<sup>45</sup> and an expensive diagnostic process that increases in cost with the stage of disease.<sup>7</sup> Many initiatives (e.g., Health Education England's e-learning for healthcare programmes) have begun to increase awareness of signs and symptoms of a wide range of cancers.<sup>46-49</sup> The International Agency for Research on Cancer (IARC) and the World Health Organization (WHO) have also published a consensus for the classification of NENs, which recognises the key differences between NETs and NECs, including the different symptoms experienced.<sup>2,50</sup>

**Low awareness, fear, and symptom dismissal:** Research has highlighted that concerted action is needed to improve awareness among healthcare professionals and the English population in regard to all symptoms for rare or less common cancers, such as NENs.<sup>35,51</sup> Limited recognition of symptoms, as well as fear of being diagnosed with cancer, can lead to delays in diagnosis.<sup>5,35,51</sup> Several surveys have reported the time from first symptom to diagnosis as over 50 months in UK-based and global NEN populations, often owing to incorrect initial diagnoses and low recognition of symptoms.<sup>5,52,53</sup> Such delays are compounded by limited specialist training in NENs.<sup>40</sup> The current National Institute for Health and Care Excellence guideline for suspected cancer pathways does not include NENs, despite the fact that many of the symptoms it highlights can be attributed to NENs.<sup>54</sup> As a result, differentiating a potential malignancy from other benign diseases can be challenging.<sup>55</sup>

The number of formalised non-specific symptom referral pathways implemented under the leadership of local Cancer Alliances has seen a recent increase.<sup>56</sup> This is a step in the right direction to include those who do not fit within a current designated cancer care pathway, improving the likelihood of appropriate care.<sup>57</sup> However, these pathways do not yet cover all geographies or symptom presentations.<sup>56,57</sup>

### 3.1.2 | Testing, diagnosis and grading

The NHS England Faster Diagnosis Standard outlines that all people in England should either have a diagnosis or have cancer ruled out within 28 days of being referred by their GP, or by the National Screening Service, for suspected cancer.<sup>58</sup>

A combination of tests and investigations, based on an individual's symptoms and medical history, are needed to confirm an NEN diagnosis.<sup>59</sup> Tests may include endoscopic procedures, radiological and/or radionuclide imaging scans, blood and urine analyses and histopathology (e.g., tissue biopsy).<sup>59</sup> Determining the primary site, disease distribution and grade of cancer is vital to inform treatment decisions.<sup>59</sup> Grading of NENs refers to the number of proliferating cells within the cancer and subsequently provides an indication of prognosis, likelihood of metastasis and potential comorbidities.<sup>60</sup> The IARC/WHO classification of NENs outlines that the higher the grade, the greater the urgency to commence treatment.<sup>2,50,60</sup>

#### Barriers to care

**Limited access to appropriate diagnostic testing:** Before receiving an NEN diagnosis, individuals in the UK visit their GP an average of 11 times over a mean period of 37 months.<sup>5</sup> Such delays and other significant challenges faced by people with NENs are caused by the diversity of NENs and restricted access to relevant diagnostic tools and specialists.<sup>5,35,39</sup> The limited number of radiologists and other healthcare workforce available to support diagnosis also exacerbates current inequities.<sup>61,62</sup>

There is an uneven distribution of NEN diagnostic facilities across the UK, in particular molecular radiotherapy imaging (e.g., Ga-68 positron emission tomography [PET] scans).<sup>63,64</sup> Additional barriers in access are caused by the centralised commissioning of PET and computed tomography (CT) scanning.<sup>65</sup> These are unlike other diagnostic imaging modalities, and rigorous evidence is required to show the clinical and cost-effectiveness of interventions through improvements in patient outcomes.<sup>65</sup> The cost efficiency of PET/CT scanning has been demonstrated for the management of a few cancer types in a number of countries,<sup>66</sup> including for the long-term management of head and neck cancers in the UK.<sup>67</sup> The scans have been found to reduce treatment costs and delays in detection, with the use of Ga-68 PET scans confirmed as a cost-effective strategy for NEN diagnosis in the US health system.<sup>68</sup> However, the availability of PET/CT scans is influenced by a variety of factors, including different levels of publicly funded coverage, waiting list lengths, access to other imaging modalities, staffing, security of the radiopharmaceutical supply, and evidence-based guidance.<sup>69</sup> Continuous cost efficiency analyses are required to reflect the most up-to-date practice and ensure appropriateness of testing. For example, according to the *ENETS 2017*

consensus guidelines for the standards of care in neuroendocrine tumours, fluorodeoxyglucose-PET and Ga-Dotatate-PET scans may be used in combination at diagnosis, to establish appropriate NEN grading.<sup>70</sup>

Access to reliable testing also varies based on the type of NEN being assessed. The reliability of diagnostic tests can differ for people with functioning (excessive hormone release) and non-functioning (inactive or insignificant hormone production) NENs.<sup>71,72</sup> For example, median plasma chromogranin A (CgA) levels (which are the most widely used biochemical biomarker in gastroenteropancreatic NENs diagnosis and follow-up<sup>73</sup>) at diagnosis are significantly higher for functioning tumours when compared with non-functioning tumours.<sup>73</sup> Universal biomarkers have not yet been established for non-functioning NENs, making diagnosis more challenging.<sup>71,74</sup> There is some debate over whether the biomarker tests that are currently available are more cost-effective than other modes of testing; further innovation and efficiencies in biomarker testing would be required to confirm cost-effectiveness.<sup>71</sup> Research in this area is accelerating, and the NETest (a biomarker test analysing NEN gene expression) has demonstrated a significant advantage over other molecular biomarkers in the diagnosis and monitoring of NENs, including circulating CgA.<sup>71</sup> A study of people with a variety of NET types found that upon application of a post-operative NETest, recurrence was predicted with 94% accuracy and subsequent stratification of post-surgical imaging resulted in a cost-savings of 42%.<sup>75</sup> More studies are needed to confirm the general cost-effectiveness of the NETest, and whether it can be widely introduced, since only a small number of laboratories are currently able to perform the analysis.<sup>71</sup>

A more appropriate cost-effectiveness standard and greater commitment to data collection and research, alongside an even distribution of specialist diagnostic services, would likely improve the timeliness of NEN diagnosis. This would align with Cancer Research UK's Early Diagnosis Programme,<sup>76</sup> and the NHS Faster Diagnosis Framework's core principles of early identification, broad assessment of symptoms, coordinated testing, timely diagnosis and appropriate onward referral.<sup>56</sup>

**Inaccurate NEN grading:** Correct classification of NENs has clear prognostic implications.<sup>2</sup> The increased biological understanding of NENs<sup>37,77</sup> and standardisation of terminology in recent years<sup>78</sup> has underpinned the importance of accurate NEN classification (using histopathology and other prognostic and therapeutic markers). These developments have also established the need for experienced healthcare professionals (updated on the latest knowledge), to ensure all NENs are accurately graded.<sup>6,38,50,79–81</sup> Current and future research in these areas, including regional and national genomics initiatives,<sup>37</sup> will only help to further improve clinical effectiveness, cost-effectiveness and efficiencies in both diagnostic and therapeutic endeavours.

### 3.1.3 | Referral to a specialist MDT and treatment

According to the *Handbook to the NHS Constitution for England*, people with suspected cancer of any type should experience a maximum

62-day wait from urgent referral for suspected cancer, or consultant upgrade, or urgent screening referral, to first treatment.<sup>25</sup> A maximum 31-day wait between the decision to treat and the first definitive treatment is also promised.<sup>25</sup>

MDTs use recognised guidelines and—by reviewing all available data (e.g., histopathology)—a holistic, personalised approach to determine an effective disease management strategy for people with suspected or diagnosed NENs.<sup>40,82–85</sup> According to the ENETS Center of Excellence criteria, an MDT for NENs should include healthcare professionals with NENs experience—including physicians, site-specific surgeons, medical and clinical oncologists, radiologists and specialist nurses.<sup>36,83,86</sup> These individuals, in addition to primary care staff and others, play vital roles in NENs care.

Treatment for NENs is determined by the tumour's primary site, grade and distribution of disease,<sup>87,88</sup> alongside consideration for the individual's overall health and quality of life.<sup>89</sup> The cost efficiency of different treatment types, as well as the order and combination of treatments administered, should also be considered to ensure optimal care for people with different NENs. Treatment options vary accordingly and may include surgery, chemotherapy, interventional radiology, somatostatin analogues (SSAs), targeted molecular medical therapies, endoscopic therapies and/or radiation-based therapies.<sup>89</sup> Clinical trials may also be considered.<sup>89</sup>

Expert guidelines indicate that surgery and/or select endoscopic interventions may be the first choice for the removal of early-stage NENs.<sup>70,87,88,90</sup> SSAs,<sup>91</sup> targeted molecular medical therapies,<sup>92</sup> and radiation-based therapies (such as peptide receptor radionuclide therapy)<sup>93</sup> are some of the treatments used in NETs. In England, the use of Lutetium oxodotreotide (<sup>177</sup>Lu-Dotatate) has been shown to be a cost-effective treatment option for people with progressive gastroenteropancreatic NETs.<sup>94,95</sup> Meanwhile, chemotherapy may be a first- or subsequent-line therapy used in NECs.<sup>92</sup> However, the care and sequence of treatments that patients receive may vary, as NENs management guidelines present different optimal treatment approaches<sup>70,87,88</sup> and not all therapies are appropriate, licenced, cost-effective or authorised for all NENs.<sup>89</sup> For example, researchers in the US have found there is no cost-benefit to administering SSAs prior to NENs progression.<sup>96,97</sup> It is important to note this conclusion may not be the same for health systems with different funding mechanisms to the US.

#### *Barriers to care*

**Poor awareness of the referral process and onward care:** Referring healthcare professionals may not be aware of the presence of local/regional specialist MDTs for NENs or ENETS Centers of Excellence.<sup>35,39</sup> In the absence of a nationally adopted care pathway,<sup>83</sup> there may be a lack of awareness around the criteria, timing or appropriateness of referral, the referral process itself, or concerns around the accessibility of care.<sup>35,39</sup> Delays and challenges in accessing disease-specific MDTs and expertise may result in people not receiving timely and appropriate care. These issues can place additional burden on the health system through increased clinical complexity and patient dependence on services.<sup>35,39</sup> These factors can also cause

increased anxiety and uncertainty for people with NENs, leading to feelings of confusion and isolation.<sup>35,39</sup>

**Varied MDT location and composition:** European-level studies have demonstrated that the care people with NENs receive at specialist centres improves both the management of people with the disease and their outcomes.<sup>98,99</sup> However, there is uneven geographical distribution of ENETS Centers of Excellence and specialist NEN centres across the UK, resulting in limited access to high-quality multidisciplinary care and treatment for people living with NENs.<sup>100,101</sup> The widely reported issues in the availability of NHS staff,<sup>62</sup> including cancer care specialists, are also amplified for rare conditions such as NENs.<sup>51</sup> Therefore, initiatives such as the UKINETS annual 'NETs for Newcomers' course,<sup>102</sup> ENETS European Board of NEN Medicine initiative,<sup>103</sup> and the Neuroendocrine Cancer Nurse Competency Framework (accredited by the Royal College of Nursing)<sup>104</sup> aim to educate healthcare professionals. Yet these only go some way to support the workforce required to appropriately care for people with NENs across the country.

**Complex funding challenges:** The absence of a single patient care pathway and specialised commissioning for NENs severely limits the accessibility and availability of both commonplace and pioneering NEN treatments.<sup>35,63,83</sup> As a result, those with advanced disease or highly complex needs, or those facing social disadvantage, can incur significant travel or personal costs if they do not live near a specialist MDT or ENETS Center of Excellence.<sup>39,105</sup> Specific concerns have also been documented for particular treatments, as well as the scans which can guide them. For example, there have been many calls to secure appropriate funding and commissioning for equitable access to molecular radiotherapy services in the UK.<sup>64,106-111</sup> Similarly, it has also been flagged that there is a need for expansion of the eligibility criteria for clinical trials<sup>112,113</sup> to align with the NHS ambition to better embed clinical research delivery into UK health systems.<sup>114</sup>

### 3.1.4 | Follow-up care and ongoing treatment

For all first treatments, and many subsequent treatments, people in England should have a maximum 31-day wait from the decision-to-treat, according to the *Handbook to the NHS Constitution for England*.<sup>25</sup> For any subsequent treatments that are part of a secondary phase of a pre-agreed plan, the 'earliest clinically appropriate date' is used as the start date for this treatment period.<sup>25</sup>

For many people with an NEN diagnosis, follow-up care is lifelong and subsequent treatment is likely needed over time.<sup>70,87,88</sup> Many aspects of a person's condition can inform their follow-up, including the organs affected, NEN grade, stage, treatment effects and medical history.<sup>70</sup> For example, for people with stage II-III NENs, follow-up CT scans can be biannual for up to 5 years; for stage IV disease, radiological monitoring can last for many more years.<sup>7</sup> In addition to the physiological and practical challenges, the psychological burden of living with the uncertainty of an NEN diagnosis, both short- and long-term, can be significant.<sup>35,39,55,115-117</sup>

### Barriers to care

**Inconsistent and inappropriate care:** Follow-up care and ongoing treatment are directly affected by barriers to care at earlier stages in the care pathway. As a result, people with NENs often experience a different frequency and quality of follow-up care, largely due to differences in resource availability, funding and numbers of adequately trained personnel.<sup>35,37,52,57,63</sup> Evidence-based, site- and grade-specific clinical guidelines have been published to advise on the recommended type and interval of follow-up investigations.<sup>70,87,88,101</sup> However, the European clinical practice guidelines for NENs acknowledge that there is a lack of standardised follow-up regimens,<sup>70,87,88</sup> leading to uncertainty in determining cost-effectiveness. For example, the care for people with carcinoid syndrome (the abnormal production of peptides and/or hormones (e.g., serotonin) caused by NETs<sup>118</sup>) is known to incur high costs, but studies exploring this are limited.<sup>119</sup>

While clinical guidelines do exist, their effectiveness is a function of the latest available information, and where data on the most appropriate care are lacking, guidance may prove inappropriate. As previously mentioned, cost-effective and highly sensitive biomarker testing for NENs is yet to be realised.<sup>71</sup> This is reflected in the limited details given in European guidelines on the biomarker testing required during follow-up care; moreover, the guidelines' recommendations are not differentiated for functional and non-functional NENs.<sup>70,88</sup> A number of circulating biomarkers have been identified as potentially relevant in the follow-up care of people with NENs, for example:

- For people with metastatic NETs and/or carcinoid syndrome, 5-hydroxyindoleacetic acid can indicate a biochemical response to SSA treatment and may be useful in detecting recurrence post-surgery.<sup>71</sup>
- For people with gastroenteropancreatic NENs, CgA has been found to be more reliable when used to monitor disease progression and response to treatment, rather than in the diagnostic setting.<sup>120</sup>

Yet, it is clear that more research and guidance are needed to support cost-effective and personalised follow-up care.

Experts have begun compiling and analysing a wealth of patient data through the ENETS database<sup>121</sup> to ensure future follow-up guidelines are better informed and make services more efficient and cost-effective. These data can also be used to support effective implementation and tailoring of the NHS personalised, stratified follow-up pathways.<sup>9,122,123</sup>

**Challenges posed by personalised care:** As care becomes increasingly personalised during follow-up, the impact of language, literacy, financial and cultural barriers on care-seeking behaviours,<sup>39</sup> mental health and, ultimately, clinical outcomes of people living with NENs is amplified. These challenges have been exacerbated by the COVID-19 pandemic, which had adverse effects on the mental health of people living with NENs.<sup>55,124-128</sup> A 2020 survey found that people undergoing longer-term follow-up for NENs experienced greater anxiety and decreased psychosocial wellbeing during the pandemic, as well as a greater reluctance to seek out care.<sup>124</sup> Maggie's Centres and NCUK

provide free counselling and psychotherapy services to help people with NENs talk through their concerns, including finances, treatments and MDT care.<sup>129,130</sup> These initiatives support the ambitions of the NHS Long Term Plan,<sup>9</sup> but more support is needed.<sup>55,84,113</sup>

### 3.2 | Patient care pathway for neuroendocrine cancer

Figure 4 presents the patient care pathway, structured in line with the NHS Constitution for England<sup>24,25</sup> and informed by the current literature and extensive consultation with multidisciplinary experts. It outlines the different phases of care that can be expected from the point of suspicion through to follow-up treatment.

## 4 | DISCUSSION

The patient care pathway could make significant improvements for people with NENs, wider patient groups and indeed the health system as a whole. By clearly outlining the process a person will go through and expected timelines, the pathway provides a framework for healthcare professionals, people with NENs and their families to pursue the right care, in the right place, at the right time.

Implementing change in health systems with strict budgets requires a considered and measured approach. The economic implications of policy decisions related to NEN care must be carefully considered to ensure effective and sustainable change. The introduction of a care pathway can increase efficiency by ensuring that healthcare professionals follow the appropriate approach to diagnosing NENs and developing a management plan. For example, this pathway provides the consensus view that grading should be completed prior to treatment plans being confirmed.

Furthermore, at each stage along the care pathway, cost-efficiency can be maximised through a comprehensive understanding of the patient population, health system capacity and resources, as well as the most appropriate diagnostic tools, treatments and supportive care interventions. There is some evidence of the cost-effectiveness of specific treatments for NENs,<sup>94,95,131–137</sup> and cost-efficiency of care pathways for other conditions has been demonstrated.<sup>13–18</sup> It is important to note, however, that there is currently insufficient evidence on the cost-effectiveness of many types of NEN management.<sup>7,138</sup> More data on management options are required.

Effective implementation of the pathway within NHS England practice would

- likely reduce overall health system costs for people with NENs and improve quality of life
- raise awareness of the barriers to care faced by people with NENs and how these may be overcome
- help ensure clarity among the variety of healthcare professionals involved in the care of people with NENs, particularly regarding the appropriateness of diagnostic tests and treatment

- improve the timeliness of NENs diagnosis, particularly if coincided with systematic implementation of the existing NHS England timed rapid diagnostic and assessment pathways<sup>27–30</sup>
- inform appropriate holistic-needs assessments and care plans, support the assignment of a clinical nurse specialist, and health and wellbeing support for effective and personalised care, as outlined in *The NHS Long Term Plan*<sup>9</sup>
- contribute to the wider efforts across the health system to spread effective service models, standardise diagnostic and treatment approaches, and ensure optimal use of existing resources and expertise
- support Integrated Care Systems (ICSs), Cancer Alliances and other NHS bodies to work collaboratively and create clear points of contact for people with NENs, as well as establishing effective communication channels between healthcare professionals, especially during follow-up<sup>55,57,139</sup>
- help reduce the inequities faced by people living with NENs, particularly in the absence of specialised commissioning.<sup>35,63</sup>

We are aware that implementation of the patient care pathway alone cannot address all of the challenges faced. Therefore, building on the known barriers to optimal care and existing work to overcome them, we propose policy recommendations for each stage of the pathway to assist healthcare providers and decision-makers in beginning to make change (see Figure 5). To ensure optimal care pathway implementation, these recommendations should be adopted along with an appreciation of the growing evidence of the most cost-effective interventions at every stage.

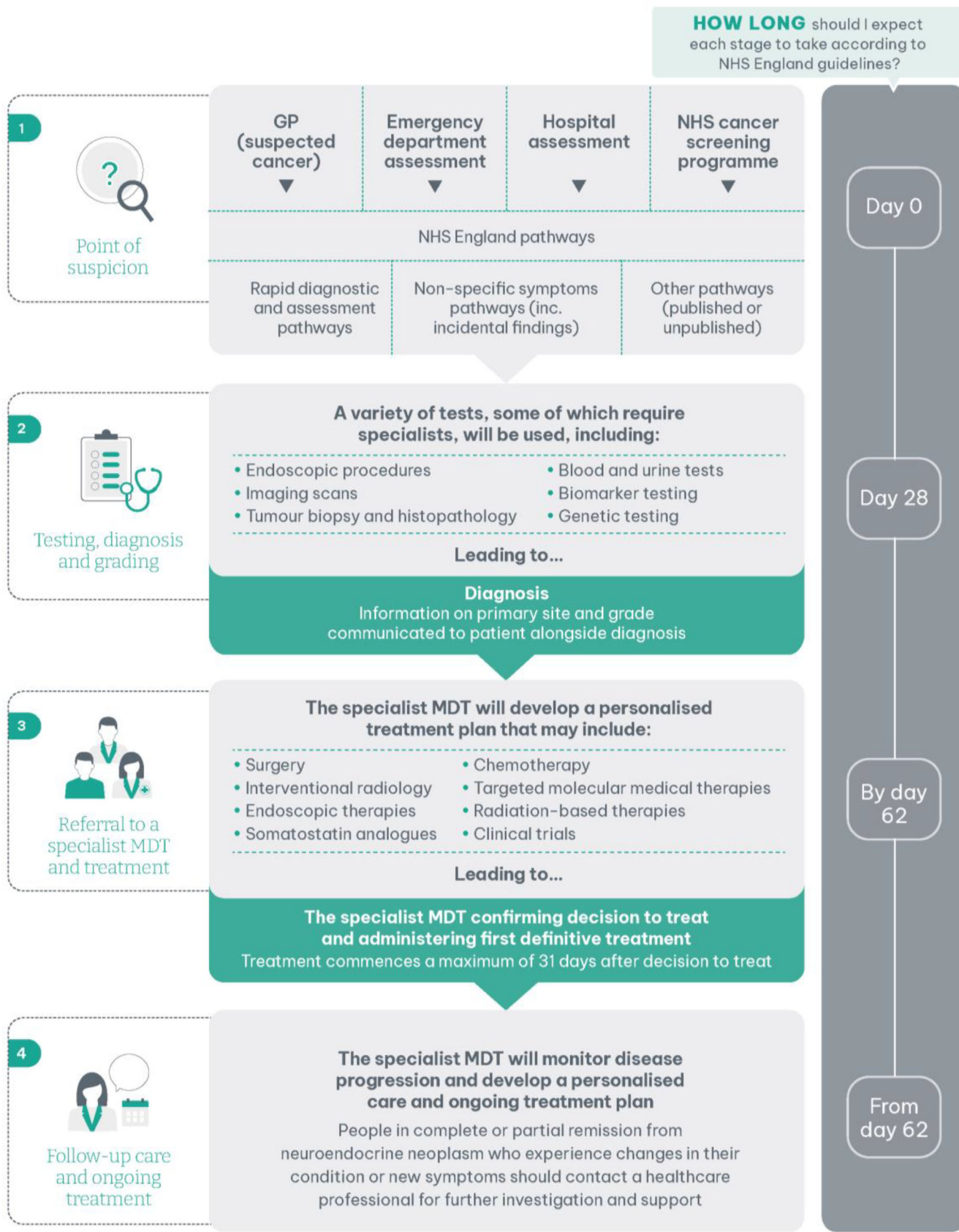
The cost of implementing the care pathway for neuroendocrine cancer can be relatively minimal as many of the barriers to care identified during pathway development can be overcome by including NENs in existing initiatives. Such inclusion requires raising awareness via ongoing communications with healthcare commissioners. Communications should feature unified messaging, despite the diversity in symptom presentation and disease management. Once awareness is increased among health system leaders and healthcare professionals, the condition would be more easily recognised and included in regional strategies and national plans. At this stage, it would be beneficial to increase investment in data collection to further refine options for treatment management.

In England, the care pathway and policy recommendations should be implemented via consistent communication with Cancer Alliances and ICSs, which commission and organise services in different regions.<sup>140,141</sup>

The patient care pathway also serves as a useful starting point for streamlining and improving NEN care in other nations. Across the globe, many similarities exist in the care required by, and available to, people with NENs.<sup>113</sup> For example

- The complex diagnostic journey for people with rare diseases is internationally recognised, with individuals often waiting several years for an accurate diagnosis.<sup>142</sup>
- Globally, depression and anxiety among people living with cancer is a growing problem along the entire care pathway, with people often not receiving the care they need.<sup>143</sup>





GP, general practitioner; MDT, multidisciplinary team; NHS, National Health Service

**FIGURE 4** Patient care pathway for neuroendocrine cancer.<sup>22</sup>



### Point of suspicion

- Continue to support, participate in and roll out initiatives to increase awareness of symptoms for cancer (such as Cancer Research UK's 'Talk Cancer' training programme) and NENs specifically
- Reference the patient care pathway for neuroendocrine cancer in relevant disease-specific and non-specific symptoms pathways, and include NENs in the National Institute for Health and Care Excellence guideline for suspected cancer



### Testing, diagnosis and grading

- Ensure Cancer Alliances' and Integrated Care Systems' (ICSs) NENs diagnostic practice aligns with the core principles of the NHS Faster Diagnosis Framework
- Invest in infrastructure to support diagnosis of rare cancers and establish a more even distribution of specialist services (e.g. positron emission tomography (PET) scans)
- Continue to support and develop work facilitating early integration of genetic and genomic advances into diagnostic pathways



### Referral to a specialist MDT and treatment

- Roll out the patient care pathway for neuroendocrine cancer across ICSs and Cancer Alliances in England
- Support and expand existing training programmes to inform healthcare professionals about NENs (e.g. UKINETS 'NETs for Newcomers' course, ENETS European Board of NEN Medicine (EBNEN) initiative)
- Accelerate academic and clinical research into the optimal types and order of treatments for different NENs



### Follow-up care and ongoing treatment

- Apply lessons learnt from the implementation of NHS personalised stratified follow-up pathways to follow-up care for people with NENs
- Further develop existing initiatives and novel interventions that support accessible and holistic follow-up care for all people diagnosed with a NEN (e.g. Neuroendocrine Cancer UK's free counselling and psychotherapy service, and group therapy programmes)

**FIGURE 5** Policy recommendations that will help overcome the barriers identified at each stage of the patient care pathway.<sup>22</sup>

- In 2020, researchers predicted that the demand for PET-CT scans for cancer management is not being met in at least 96 countries.<sup>144</sup>
- England is one of 22 countries that has certified ENETS Centers of Excellence,<sup>100</sup> and the common standards among these centres mean that many of the recommendations for support of ENETS initiatives and ongoing care management in this article will be relevant elsewhere.

The cost-efficiency of implementing care pathways for various disease areas and patient groups has been demonstrated,<sup>13-18</sup> and experts

acknowledge the role of national care pathways in improving the survival and care of people with NENs.<sup>21</sup> Health systems are incredibly diverse, which can make it difficult to compare the cost-effectiveness of the patient care pathway in different countries. However, shared data and learning can be used to support effective implementation, and to guide the ordering of specific interventions. We hope that the data that supports this care pathway, and the suggestions for its implementation, are useful for others around the globe.

The authors acknowledge that the pragmatic approach to data collection has limitations. First, as CBE and NJ provided many

materials (including published and unpublished work) at the commencement of the project, a top-up literature review was conducted with a streamlined methodology. As a result, some relevant studies may not have been identified. This risk was mitigated by asking experts about potential literature of interest during interviews; however, we are aware that there was selection bias in recruiting interviewees. Namely, where two stakeholders had similar credentials, priority for outreach was given to those who had been previously engaged with, followed by those with publicly available contact details, to maximise the likelihood of a response.

## 5 | CONCLUSIONS

All people with NENs should be able to receive efficient, effective, evidence-based and personalised care, regardless of where they live.

Effective integration of the patient care pathway for neuroendocrine cancer within NHS practice will drive improvements in outcomes, reduce delays in treatment, support specialist MDT provision, and help efforts to tackle the numerous inequities in care provision across England. This will improve the experience of people living with NENs. Furthermore, it will also optimise current infrastructure and resources, which will, in turn, go some way towards lessening the social and economic burden of NENs on the health system. This approach may be replicated in other settings across the globe by tailoring the patient care pathway to a given health system and, crucially, considering how the pathway may be implemented for the population in the most cost-effective way.

As the first dedicated patient care pathway for people living with NENs in England, which we anticipate will evolve, it has the potential to address the barriers to care that people with NENs experience at each stage. We hope all stakeholders involved in planning and delivering care for NENs can start applying the pathway in their own services and nationally.

### AUTHOR CONTRIBUTIONS

**Jessica Hooper:** Conceptualization; investigation; methodology; project administration; visualization; writing – original draft; writing – review and editing. **Nikie Jervis:** Validation; visualization; writing – review and editing. **Lucy Morgan:** Conceptualization; investigation; methodology; project administration; supervision; visualization; writing – original draft; writing – review and editing. **Vivienne Beckett:** Validation; visualization; writing – review and editing. **Phillippa Hand:** Validation; visualization; writing – review and editing. **Kate Higgs:** Validation; visualization; writing – review and editing. **Alia Munir:** Validation; visualization; writing – review and editing. **Jenny Prinn:** Validation; visualization; writing – review and editing. **D Mark Pritchard:** Validation; visualization; writing – review and editing. **Debashis Sarker:** Validation; visualization; writing – review and editing. **Raj Srirajskanthan:** Validation; visualization; writing – review and editing. **Catherine Bouvier Ellis:** Funding acquisition; validation; visualization; writing – review and editing.

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#### PEER REVIEW

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#### DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon request.

#### ORCID

Jessica Hooper  <https://orcid.org/0000-0003-1829-429X>

Lucy Morgan  <https://orcid.org/0000-0002-6679-454X>

D Mark Pritchard  <https://orcid.org/0000-0001-7971-3561>

Debashis Sarker  <https://orcid.org/0000-0003-4814-8429>

Raj Srirajaskanthan  <https://orcid.org/0000-0001-9835-8681>

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