Written evidence submitted by the Less Survivable Cancers Taskforce (ECS0021)

Introduction

Thank you, on behalf of the Less Survivable Cancers Taskforce (LSCT), for the opportunity to inform the Expert Panel's evaluation of the progress the Government has made against its commitments in cancer services.

The Less Survivable Cancers Taskforce is a coalition of charities representing each of the six most common less survivable cancers:

- Lung cancer – Roy Castle Lung Cancer Foundation
- Stomach cancer – Guts UK
- Oesophageal cancer – Action Against Heartburn
- Brain cancer – The Brain Tumour Charity
- Pancreatic cancer – Pancreatic Cancer UK
- Liver cancer – British Liver Trust

More than 90,000 people are diagnosed with one of these cancers every year in the UK. They make up a quarter of all diagnoses, but more than 40% of cancer deaths because of their poor survival rates. These cancers have not seen the improvements in diagnosis, treatment and care that other cancers have in recent decades and only 16% of people diagnosed with a less survivable cancer will survive for 5 years or more.

The LSCT are concerned that, by creating pan-cancer commitments, ambitions and targets, the less survivable cancers will continue to be overlooked and under-resourced. We believe that specific commitments and targets for the less survivable cancers are needed to drive forward the transformational changes we need in diagnosis, treatments and care required in these cancer areas.

We have answered below the most relevant questions from your planning grid and would be happy to provide any additional information as required.

1. Workforce

Commitment: The Cancer Workforce Plan committed to the expansion of capacity and skills by 2021

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

Cancer workforce development is central to improving patient experience and outcomes and reducing delays and waits for diagnostic tests and treatments.

We support Macmillan's following key recommendations on workforce, in order to execute the Cancer Workforce Plan:

- The Secretary of State for Health must ensure that the NHS has the sustainable nursing workforce required to deliver the care people living with cancer need.
- NHS England, NHS Improvement and Health Education England must urgently deliver a costed cancer workforce plan. This must be based on realistic estimates of the workforce numbers that will be required to meet the needs of people living with cancer.
- NHS England, NHS Improvement and Health Education England must act urgently to boost the supply and retention of the general adult nursing workforce. This is necessary to ensure all nurses have backfill for their clinical commitments to undertake CPD; and to ensure a pipeline for specialist nursing roles.
- Health Education England's CPD budget should be restored, as a minimum, to its former highest level of £205m.

The last Cancer Workforce Plan rightly recognises the critical and positive role of Cancer Clinical Nurse Specialists (CNS) to patient experience. We absolutely agree with this and believe that every person diagnosed with a less survivable cancer should have a CNS assigned.

However, data from The Brain Tumour Charity's Improving Brain Tumour Care surveys collected in October 2021 showed that out of a sample of 1487 people diagnosed or in active treatment during the last 2 years, **only 79% of respondents were given a named person (keyworker or CNS)** who could answer questions, address worries and fears or help provide support. And only 59% of respondents who had a CNS felt they had good access where they could ask them anything at anytime. This is extremely worrying and shows many patients are not having the questions they need answered or signposting to the support they require.[1] It is vital that UK Governments invest in the cancer workforce to ensure access to a CNS is increased to 100%, as a named healthcare worker is crucial for continuity of care and support for those living with brain tumours.

We would like to see each person with a less survivable cancer be assigned to a CNS with expertise in their cancer. For example, we often hear that people with pancreatic cancer are often assigned to UGI CNS who do not necessarily have expertise on HPB/pancreatic cancer.

2. Diagnostics

Commitment: A faster diagnosis standard from 2020 to ensure most patients receive a definitive diagnosis or ruling out of cancer within 28 days of referral from GP or from screening

[1] Sample: 1487 people diagnosed or in active treatment during the last two years.

Commitment: By 2028 the proportion of cancers diagnosed at stages 1 and 2 will rise from around 50% now to 75% of cancer patients

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

2. Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?

The early diagnosis ambition

The early diagnosis commitment is not on track to be met. This has been exacerbated by Covid-19, but the NHS was not on track to meet the target before March 2020.

In order to achieve the target of diagnosing 75% of all cancers at stages 1 or 2, significant focus and investment in improving earlier and faster diagnosis in the less survivable cancers is needed. Currently only 25% of people with our cancer types are diagnosed at stages 1 and 2 (compared to the pan-cancer average of 55%). Therefore, the aim to diagnose 75% of people with cancer diagnosed at an early stage by 2028 is welcome but completely unachievable without a clear focus on diagnosing people with less survivable cancers earlier.

We therefore believe that a specific commitment or ambition for improving early diagnosis rates for less survivable cancers would drive forward these necessary improvements. Initiatives and policies that should be prioritised are:

- **Lung cancer screening should be accelerated:** Certain population groups are at high-risk of specific LSCs, and we welcome the acceleration of lung cancer screening pilots. Rolling out screening, and ensuring lung cancers services are ready to accommodate an increase in referrals, must be a priority.
- **Earlier diagnosis of people with liver cancer must be addressed through effective surveillance of patients with cirrhosis:** The majority of liver cancer patients are asymptomatic, but more than 80% of people with liver cancer have pre-existing liver disease. People who are diagnosed with cirrhosis should receive ultrasound scans and blood tests every six months to monitor for primary liver cancer (HCC). A robust system is needed so that all those deemed to require surveillance undergo a six-monthly ultrasound scan, followed by mechanisms for recall and further investigation if an abnormality is found.
- **Roll out of Cytosponge to diagnose Barretts Oesophagus and relieve pressure on endoscopy services:** We are pleased to see the commitment to rolling out Cytosponge, as is happening in Scotland, and urge this to be taken forward as a priority.
- **Roll out of a national surveillance programme of people with hereditary pancreatic cancer**: About 10% of pancreatic cancers are hereditary and mainly among people with first-degree relatives diagnosed with pancreatic cancer. The NICE guidance on diagnosis and management of pancreatic cancer in adults (NICE NG85)14 includes a recommendation to offer surveillance for pancreatic cancer to people with:
    a) hereditary pancreatitis and a PRSS1 mutation,
    b) BRCA1, BRCA2, PALB2 or CDKN2A (p16) mutations, and one or more first-degree relatives with pancreatic cancer
    c) Peutz–Jeghers syndrome

  However, surveillance of people with hereditary pancreatic cancer is not funded by NHSE/I but instead people are mainly screened as part of research studies such as the EUROPAC in

Liverpool. This is a significant limitation as not all people at risk across the country are offered screening. NHSE/I should allocate funding to ensure that everyone at risk of familial pancreatic cancer has access to a surveillance service through the NHS no matter where they live in England as recommended in the NICE NG85 guidance. NHSE/I should also closely work with EUROPAC to better understand the risk of familial pancreatic cancer and the potential adoption and scaling of current study protocols to appropriately triage patients on to surveillance pathways.

In addition, to meet the early diagnostic target, investment is needed in **new diagnostic technologies and tests that can help to diagnose these cancers in easier, less intrusive ways.**

There is currently no simple test or a tool for less survivable cancers to timely identify symptomatic people who need further investigation. For example, pancreatic cancer presentation is characterised by vague and non-specific symptoms that have a low probability to be cancer. Therefore, there is a regular delay between first presentation of symptoms at the GP and referral for diagnostic tests leading to multiple visits and diagnosis at a late stage. People with pancreatic cancer present a median of three occasions with alarming symptoms in the two years prior to diagnosis, with half (51%) re-attending with the same symptom and 75% re-attending with an alternative alarm symptom. It has been shown that 91% of patients had relevant symptoms in the two years prior to their diagnosis.

We believe that NHSE/I should provide funding and work with the primary care cancer research community (for example Professor Julia Hippisley-Cox at Oxford University) on refined versions of GP decision making tools such as QCancer tool. QCancer has been designed with the aim of developing machine learning / algorithm tools to identify combinations of symptoms in health records which, in turn, generate a risk score and a red flag for pancreatic cancer and other less survivable cancers. This pathway could be designed to be supplemented by future pipeline innovations such as the triage breath test.

Moreover, there should be investment in systematic research to identify, image and monitor people at increased risk for less survivable cancers such as pancreatic cancer. Specifically for pancreatic cancer, increasing evidence shows that some conditions increase the risk of developing pancreatic cancer. For example, new onset of diabetes, pancreatitis and asymptomatic cystic lesions of the pancreas are all associated with an increased risk to develop pancreatic cancer. However, given that a small proportion of those will develop pancreatic cancer (approx. 1% for New Onset Diabetes (NOD), 6 – 8 times higher than the general population), it is not sustainable to screen whole populations with each one of these risk factors. Further work is needed to define the populations with the highest risk based on a combination of factors, so we're not targeting whole populations.

Particular attention should be made to new onset of atypical diabetes that doesn't conform to that of a patient with a typical metabolic syndrome (e.g. weight gain). At the time of diagnosis, around 65% of people with pancreatic cancer have diabetes, with more than 50% having new-onset diabetes. This can occur up to two years before diagnosis and in the absence of any other symptoms, therefore, is an early warning sign for pancreatic cancer that may be missed in primary care.

The current NICE NG12 guidance recommends direct access to a CT scan for those over 60 years old with new-onset diabetes in the presence of unexplained weight loss, however this guidance is too restrictive because not all patients present with weight loss and we have seen cases of people younger than 60 also present with these symptoms. There is scope to better target a population

with New Onset Diabetes (NOD), weight loss, age and other symptoms patterns/factors, who could then be referred for pancreatic cancer as part of a case finding pilot.

NHSE/I should consider investing in the development of AI / Algorithm tools to identify people in GP records with a combination of symptoms, conditions and risk factors that associated with a high risk of developing less survivable cancers, such as pancreatic cancer, which could then lead to a referral or follow up survey / set of questions to further enrich these population data. This work could start with NOD given the ongoing research of Professor Eithne Costello on future candidate biomarkers in distinguishing type 3c diabetes in people with new onset diabetes.

Faster diagnosis standard

Diagnosing people faster can contribute to earlier diagnosis through improving the efficiency and sequencing of pathways, reducing barriers between primary care and secondary care as well as widening access and providing a platform for adopting new research and innovations.

Some initiatives, such as Best Practice Timed Pathways are particularly welcome for our cancer types. They have the potential to diagnose people who present with vague symptoms faster.As well as increasing the speed of diagnosis, they are also an opportunity to highlight and drive improvements in patient care earlier in the pathway.

3. To what extent has the NHS's Covid-19 response affected progress on targets?

Covid-19 has exacerbated issues of late diagnosis across cancers as many people have not come forward to present with symptoms to their GP. Fewer presentations of people with lung cancer symptoms has been a particular problem due to the overlap of symptoms with Covid, and referrals for lung cancer are still only at 93% of what they were pre-pandemic.

As well as fewer people coming forward for referrals, during the first wave of the pandemic in particular, capacity for endoscopy (necessary for diagnosing oesophageal cancer) was seriously reduced due to it being a particularly aerosol-generating procedure and the extra cleaning required.

Data on brain cancer presentations and diagnoses over the pandemic give a good illustration of the impact:

- According to the Rapid Cancer Registration Data, there were over 320 fewer people diagnosed with brain or CNS cancer in England in 2020, compared to 2019.
- The number of people referred for investigation with suspected brain or CNS cancer in England dropped significantly in the first peak of the pandemic, with over 60% fewer referrals in April 2020, compared to April 2019. While referral numbers began to recover after the first peak, between April 2020 and March 2021 there were over 1,800 fewer urgent referrals for suspected brain or CNS cancer in England compared to the previous year, a decline of around 18%.
- Between April 2020 and December 2020, emergency presentations made up an average of 53% of all diagnoses in England, which is higher than the 47% observed pre-pandemic (January 2018- March 2020), peaking in May 2020 at 59% of all diagnoses. This rise in the proportion of people being diagnosed via emergency presentations is of significant concern and may represent one of the main impacts of the COVID-19 pandemic on brain tumour diagnosis.
- In Scotland, it is estimated that there were around 65 fewer people diagnosed with a brain tumour via pathological sample in 2020, compared to 2019 – representing an 18.5% decline.

- In Northern Ireland, it is estimated that there may have been up to 15 fewer people diagnosed with brain cancer in 2020, compared to the annual average 2017-2019 – representing a 15% decline.
- It is estimated that, in total, there were over 400 fewer people diagnosed with brain or CNS cancer in the UK in 2020, compared to 2019. This is incredibly worrying as this could be an indicator of a much larger backlog problem heading our way, or that people are putting off visiting their GP with symptoms and we could end up with more emergency presentations further down the line.

Was it an appropriate commitment?

1. Was (or is) the commitment likely to achieve meaningful improvement for service users, healthcare staff and/or the healthcare system as a whole? If not, why not?

Earlier diagnosis

Clear commitments that drive improvements in diagnosing people earlier are welcome, and achieving these could be transformational for cancer outcomes.

However, the broad overarching commitment of diagnosing 75% of patients at stage 1 and 2 is so far beyond the current experience of our less survivable cancers, it is meaningless and completely unachievable without targeted focus, investment and tailored improvement strategies. Only 25% of people with our cancer types are diagnosed at stages 1 and 2, compared to the pan-cancer average of 55%. Further, 45% of liver cancer patients, 54% of pancreatic cancer patients and 30% of lung cancer patients are diagnosed at emergency settings, compared to 17% overall.

LSCs often present with vague symptoms, making them hard to diagnose and meaning that diagnosis often takes place once the cancer has already spread, thus limiting treatment options. Therefore, a focus on early detection, fast diagnosis and efficient prompt pathways to surgery and treatment is essential. In addition, research investment to improve diagnostic tests (to enable earlier and faster diagnosis) as well as improved treatment options should be prioritized.

To drive forward progress in early diagnosis for the less survivable cancers (and so that improvements in early diagnosis of other cancer areas don't mean less survivable cancers can be overlooked), we think a specific target is needed for these cancers.

Furthermore, while early diagnosis is critical, for brain tumours, performance on early diagnosis is difficult to measure in this way or address, as there is no relevant staging data in the same way as there is for other cancers. We are therefore not sure how the 75% target set by the NHS will be measured or achieved for brain tumours.

Faster diagnosis

Even when diagnosed at an early stage, less survivable cancers often nonetheless have poor outcomes due to delays in pathways, meaning that people transition from operable to inoperable due to rapid progression of their cancer**.** This rapid progression also means that, while a 28-day target may be beneficial for other cancers, it is still too long for LSCs. Investment in diagnostic capacity, fast diagnostic pathways and optimal pathways to treatment is also key.

Moreover, the Best Practice Timed Pathways (BPTP - previously known as RDCs) are currently intended for urgent cancer referrals as defined by the NICE NG12 referral criteria, however, the NG12 criteria are too restrictive for less survivable cancers such as pancreatic cancer. Pancreatic Cancer UK have consulted a wide range of health professionals across all levels of NHS such as

pancreatic cancer clinical specialists, Cancer Alliance service managers as well as patient representatives who all agreed that the pancreatic cancer BPTP should include a wider referral criteria than the NICE NG12 The NICE NG12 referral criteria could be expanded through removing the age threshold for jaundice, expanding the pattern of symptoms independent from weight loss, expanded symptom criteria for people presenting with new onset diabetes.

2. Is the commitment specific enough?

Less survivable cancers have many needs specific to their cohort, and we urge that they be treated with individualised, tailored approaches, and specific measures published that will target each less common cancer.

Currently, Faster Diagnostic Standard data for pancreatic, stomach, liver and oesophageal cancers are grouped with Upper Gastrointestinal (UGI) cancers, making it difficult to understand if the target is met for each cancer and also identify issues in the pathway. Moreover, currently there are different BPTPs for oesophago-gastric (OG) and Hepato-Pancreato-Billiary (HPB) cancers. We believe that there should be a clear distinction and alignment of the FDS data with relevant cancer BPTPs.

For brain tumours, the 28-day target has been met every month since, other than August 2021, when it fell to 70.8%. Whilst faster diagnosis will provide the clarity many patients need to explain their symptoms, it is not clear for brain tumours whether earlier or faster diagnosis is enough to lead to better survival or quality of life outcomes. This is why individualised, tailored approaches and specific measures are so important when it comes to brain tumours as well as other less survivable cancers.

The Improving Brain Tumour Care Survey (2021) showed that for 17% of respondents it took over 6 months to receive a brain tumour diagnosis after first seeing a healthcare professional for their symptoms, but 39% didn't visit their GP at all before diagnosis. 52% of respondents were diagnosed with something else first for their brain tumour symptoms.[2]

3. Living well with and beyond cancer

Commitment: By 2021 where appropriate every person diagnosed with cancer will have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support

Was the commitment met overall? or (in the case of a commitment whose deadline has not yet been reached) Is the commitment on track to be met?

2. Are there any mitigating factors or conflicting policy decisions that may have led to the commitment not being met or not being on track to be met? How significant are these? Was appropriate action taken to account for any mitigating factors?

We agree that every person diagnosed with cancer should have access to personalised care, including needs assessment, a care plan and health and wellbeing information and support.

[2] Sample: 245 people diagnosed or in active treatment during the last two years.

This should be the case for people with a short life expectancy as well as people whose prognosis is more promising and who can expect to live for a long time beyond cancer. However, we know this is not always the case. For example, The Brain Tumour Charity's (2021) Improving Brain Tumour Care Surveys showed that only 40% of respondents were offered a holistic needs assessment (HNA). With over 12,000 people diagnosed with a brain tumour every year this means thousands could be living with unmet needs due to a lack of provision of assessments and resulting care plans. The Improving Brain Tumour Care Survey also identified that only 21% of respondents felt they had a resulting care plan from their HNA that is working well. This is very worrying, and shows that many brain tumour patients have needs that are not being identified or addressed and lack the signposting to the support they require.[3]

There is a dearth of information about patient experiences and quality of life of patients with a less survivable cancer. The two most significant means of measuring cancer care, the National Cancer Patient Experience Survey (CPES) and the new Cancer Quality of Life Survey (QoL), both fail to capture patient experience for the majority of people with LSCs, meaning that their specific needs, experiences and concerns are overlooked.

Health services can only effectively improve what they can understand and measure, meaning the NHS is failing to understand and improve the experiences and quality of life of most people diagnosed with a less survivable cancer.

Limitations of CPES for people with a LSC

There is a 'survivor bias' in CPES as people are invited to take part in the survey several months after diagnosis, meaning many people with a less survivable cancer are too poorly to respond, or already possibly dead. 11% of the respondents to the 2019 CPES were from people with a less survivable cancer (7,503 respondents out of 67,858) although 25% of cancer patients have a LSC and they are responsible for 40% of the cancer deaths each year.

In addition, pancreatic, oesphageal, liver and stomach cancer respondents are combined as 'upper GI cancers' making it impossible to identify issues specific to people with each of these cancers.

Limitations of the new Quality of Life survey for people with a LSC

With the high mortality rates for patients with LSCs, most patients with a less survivable cancer will not make the 18-month mark to offer their answers to the QoL survey, and their needs and feedback into cancer services will be overlooked.

The aims of the NHS QoL metric are to track and respond to the long-term impact of cancer, and to help the NHS to support the growing number of people living with and beyond cancer.

We agree that this is a useful issue to understand, but strongly believe that a parallel metric or workstream should be developed to understand quality of life for people with a less survivable cancer. This may overlap with 'patient experience' as people are likely to be in active care when the survey is completed. This would inform further research into early supportive care needs and interventions (e.g. prehabilitation and rehabilitation). This will give a better chance to patients with a less survivable cancer to access treatment, tolerate treatment and survive as long and live as well as possible.

4. Does data show achievement against the target (if applicable)?

[3] Sample: 1158 people diagnosed or in active treatment during the last two years.

The NHS does not currently adequately capture the experiences and needs of people living with or beyond a less survivable cancer. Whilst this lack of data is a problem in itself that needs to be addressed, we have some data points and surveys that point to the need for a focus on ensuring LSC patients receive the right expertise and support at the right time.

For example, The Brain Tumour Charity's (2021) Improving Brain Tumour Care Survey highlighted that the majority of people were not informed about basic support. Only 50% of people reported they were signposted to counselling or emotional support, only 30% were offered support to access free prescriptions, only 32% were informed about financial support and benefits they could claim, and only 47% were told about support for coping with symptoms and side-effects (sample: 1257 people diagnosed or in active treatment during the last two years).

Research shows that people diagnosed with pancreatic, oesophageal and lung cancers have the second, third and fourth highest suicide risk (respectively) of all cancers and people with pancreatic cancer are nearly four times more likely to complete suicide than those diagnosed with other cancers.[4] We desperately need to find out if these patients are getting appropriate care, but this will not happen if we continue with current surveying methods. Emotional support must be integrated early into cancer care, alongside diagnosis and treatment, and regular monitoring must happen from the earliest stages of a patient's experience.

4. Innovation and technology

Commitment: Safer and more precise treatments including advanced radiotherapy techniques and immunotherapies will continue to support improvements in survival rates.

Was it an appropriate commitment?

2. Is the commitment wide enough in scope? Is it specific enough?

This is an important commitment for people with a less survivable cancer, where new treatments, tests and innovations are desperately needed to improve survival rates and quality of life.

We welcome that NHS England and NHS Improvement have now commissioned a new type of treatment for locally advanced pancreatic cancer patients. Stereotactic Ablative Body Radiotherapy (SABR) is a type of radiotherapy that delivers the radiation very precisely and from multiple angles. This approach means that the cancerous cells receive a much higher dose and surrounding healthy cells are spared. As this is a more efficient radiotherapy, people have fewer visits to the hospital and get fewer side effects.

This is really exciting progress in treatment for people with pancreatic cancer in England, but it's really important that SABR is made available across the UK. There needs to be both nationwide implementation and consistency of access and delivery across the UK, including within England itself.

Focused investment and speedy roll-outs for progress in less survivable cancers

[4] https://jamanetwork.com/journals/jamapsychiatry/fullarticle/2714596

However, in order to make the required step-change in outcomes for those with a less survivable cancer, we believe that less survivable cancers must be identified as a specific focus area for technology and innovation, with additional investment in diagnostic tests and tailored treatments.

There has historically been slow adoption of diagnostic technology and screening programmes in the NHS. For example, it took around twenty years to roll out low dose CT scanning for lung cancer for people at high risk in England. Similarly, there was a slow uptake and adoption of the cervical screening programme and human papillomavirus (HPV) testing in England. HPV screening was rolled out in 2003 in the USA, but the National Screening Committee only recommended HPV primary testing roll out in 2019. Delaying the implementation of HPV screening has been shown to miss 581 cases of cervical cancers.

Develop partnerships to create diagnostic tools that will fit into the pathway

The lack of implementation expertise of researchers and/or timely engagement with relevant experts and organisations, often means that new diagnostic innovations are developed without consideration for how they will fit within healthcare systems they are intended to be integrated into. The benefit of developing early diagnosis tests, tools and screening programmes will be greatly diminished if the right partnerships, resource, and support are not available to help researchers and clinicians implement new innovations within the NHS straight away.

NHSE/I should consider investing in building partnerships between members of the detection research community in pancreatic cancer and experts in the field of implementation research. This could be achieved through schemes that bring together and award funding specifically to multi-disciplinary research teams seeking to ensure that innovations in detection have an appropriate line of sight and can be seamlessly adopted within the NHS and cancer pathways. These formats, known as 'sandpit workshops' are very successful and have been used in the cancer detection space already. Additionally, NHSE/I could provide the research community with networking and engagement opportunities with NHSE/I to gain the insight and guidance needed to ensure a balance in outcomes, effectiveness and economics of detection innovations, accelerating the pace and increasing the efficiency of their transition out of the lab and into the clinic.

Investment in diagnostics and biomarkers

Moreover, the development of new tests for cancer biomarkers could be truly transformational in helping to diagnose people with less survivable cancers earlier and faster. UK governments and research institutes should support trials of new early diagnostic biomarkers and help embed these into pathways when successful. For example, new diagnostic triage tools, such as the *Dxcover* test (in development), need additional investment. This test has shown promise in preliminary studies having recently been found to identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours.

Better access to trials, research and biobanking

More patients need to have access to research and the opportunity to participate in research including through biobanking. Data from The Brain Tumour Charity's Improving Brain Tumour Care Survey (October 2020) showed that, out of a sample of 911 people diagnosed or in active treatment during the last 2 years, only 42% said they were informed about research and only 35% said they were participating in any research, with only 9% participating in clinical trials.

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