

Quality in Nursing
Excellence in Cancer Care:
The Contribution of the Clinical
Nurse Specialist



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MACMILLAN.**
CANCER SUPPORT

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Foreword



Together we share an ambition to achieve the best cancer outcomes for patients in the UK, recognising that, at a time of tightened budgets, it is critical that NHS resources are deployed to best effect. Now more than ever, clinical nurse specialists (CNSs) have a vital role to play in delivering high quality and compassionate care, including care closer to home, and supporting a drive for efficiency that improves health outcomes and maximises resources.

Cancer CNSs have played an important role in the successful implementation of initiatives to improve NHS cancer services. Despite an increasing incidence of the disease and an ageing population, death rates from many cancers are dropping, survival rates are improving and many patients' experiences of care have been enhanced. CNSs are at the front line of cancer care; they are the main point of contact for patients and as a result help to shape services for each patient according to need and patient choice, which contributes to wider cancer priorities. For example, CNSs play an important role in enabling care to be delivered closer to home and in improving patients' and their families' ability to self-manage symptoms and side-effects of treatment.

CNSs contribute to increasing the quality of care provided by the NHS; indeed, in the face of rising patient expectations, more patients report being treated with dignity and respect and having trust and confidence in their care team. Increasingly, they have an ongoing role in supporting cancer survivors as well as cancer patients. Overall it is estimated that there are now 2 million people living with cancer and this is set to rise to 4 million by 2030.¹

For people affected by cancer, the effective management of their care pathway is

essential to maintain quality of life. People whose care is unplanned and uncoordinated are more likely to be high users of health and social care services, including emergency

care. CNSs work closely with patients and with their clinical colleagues to adapt to patients' emerging needs thus reducing the need for unplanned care.

This short guide is designed to support clinical teams, commissioners, employers and managers to understand and evaluate the contribution of CNSs in cancer as they plan their local workforce and service improvement strategies. With examples drawn from front-line services across a range of cancers, this guide sets out how effective CNS deployment drives innovation, reduces inefficiency and improves the quality of cancer care across the UK.

We still have further to go if we are to improve outcomes for all cancers, with the aim of bringing us in line with the best in Europe. Ensuring provision of CNSs where they are needed, coupled with effective use of their skills and expertise will enable us to move faster towards this goal.

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The role of the Clinical Nurse Specialist in cancer care

The roles undertaken by Clinical Nurse Specialists (CNSs) are many and varied; however, there are core clinical practice functions and a level of practice that could be reasonably expected of all CNSs in cancer care.

CNSs in cancer care can be described as registered nurses, who have graduate level nursing preparation and who would usually be expected to be prepared at Master's level. They are clinical experts in evidence-based nursing practice within a specialty area. The specialty may be focused on a population (e.g. young people), type of care (e.g. palliative care), type of problem (e.g. lymphoedema), type of treatment (e.g. chemotherapy) or tumour type (e.g. lung cancer).

CNSs treat and manage the health concerns of patients and work to promote health and wellbeing in the patients they care for. CNSs in cancer care practice autonomously and integrate knowledge of cancer and medical treatments into assessment, diagnosis, and treatment of patients' problems and concerns.² Whilst many specialist nurses may function at an advanced level, this level of practice is not common to all, thus the title Clinical Nurse Specialist does not in itself indicate that the nurse is an 'advanced practitioner'.

The high-level activities of CNSs can be separated into four main functions.³ In the context of cancer care these consist of:

- 1 Using and applying technical knowledge of cancer and treatment to oversee and coordinate services, personalise 'the cancer pathway' for individual patients

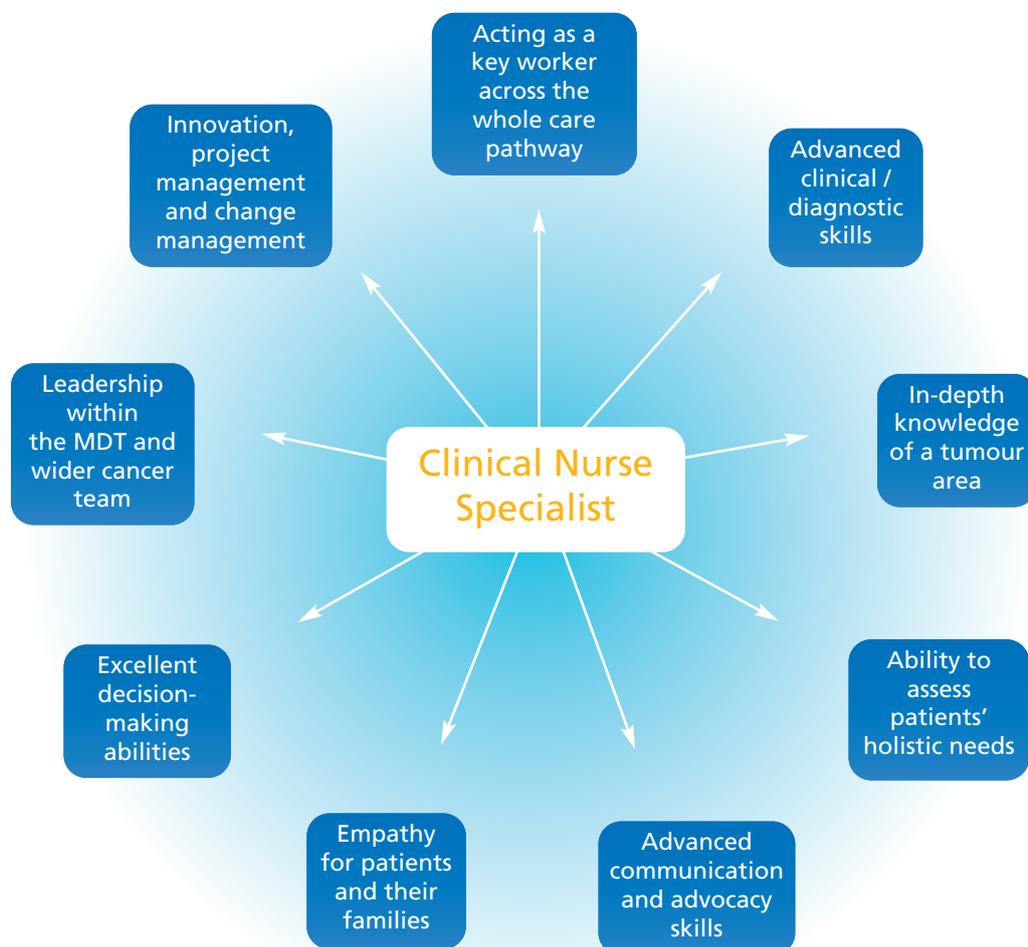
and to meet the complex information and support needs of patients and their families

- 2 Acting as the key accessible professional for the multidisciplinary team, undertaking proactive case management and using clinical acumen to reduce the risk to patients from disease or treatments
- 3 Using empathy, knowledge and experience to assess and alleviate the psychosocial suffering of cancer including referring to other agencies or disciplines as appropriate
- 4 Using technical knowledge and insight from patient experience to lead service redesign in order to implement improvements and make services responsive to patient need

Furthermore, some cancer CNSs have developed their roles to include technical elements, for example: physical examinations and diagnostic tests; and insertion of central venous lines for the delivery of chemotherapy or for nutritional purposes.

Many cancer CNSs work as part of a tumour specific team, whereas others may work across more than one service or setting. Although many are based within acute trusts, post-holders are also located in primary care and community settings or private and voluntary sector organisations. They may be responsible for whole client groups, or for episodes of care and nursing services more widely. They are also typically core members of a multidisciplinary team.⁴

Key contributions that CNSs make to cancer care



The cost of managing cancer

The cost to the NHS in England of patient care for cancer in 2007/8 was £5 billion.⁵ Department of Health figures for 2007-08 showed that:

- Over half (i.e. over £2 billion) of the total expenditure on cancer in England went on inpatient care⁶
- Inpatient care for cancer patients accounted for 12% of all inpatient beds in England⁶
- The number of emergency admissions for cancer increased by 47% in the past 8 years⁶
- 4.7 million bed days were cancer related⁶

Statistics from 2006-07 for England show:

- 417,646 emergency inpatient admissions for cancer representing 2,963,987 bed days⁶
- 339,038 elective inpatient admissions for cancer representing 1,750,223 bed days⁶

Reducing the financial burden of cancer – the potential of the CNS

The specialist nature of the cancer CNS and their role as key worker to individual patients means that they can quickly identify emerging issues that might require medical attention, enabling care to be planned and emergency admissions averted. CNSs also support enhanced recovery after surgery – equipping patients to manage their recovery at home and reducing the need for lengthy hospital stays. These two important contributions help the NHS to improve patient experience and safety.

There are also sound economic arguments for supporting patients to manage their care at home and helping them through the complex systems of health care provision.

The National Audit Office's End of Life Care report estimated £104m savings by reducing emergency admissions by 10 per cent, and reducing the length of stay by 3 days.⁷

An economic modelling analysis by Macmillan Cancer Support in 2009⁸, focusing on the role of the CNS, suggested that service improvements along the cancer pathway could release about 10% of cancer expenditure in the Manchester area. This related only to breast and lung patients admitted through the two week wait system in one health economy. If extrapolated to a national level then the economic benefits could be significant.

CNSs: leading quality and productivity in cancer care

Patients rightly expect high quality, effective healthcare and CNSs have an important role to play in meeting their needs and expectations.

The proposed NHS Outcomes Framework⁹ is structured around five high level outcome domains. These are intended to cover everything the NHS is there to do. These five outcome domains are:

- Preventing people from dying prematurely
- Enhancing the quality of life for people with long-term conditions
- Helping people to recover from episodes of ill health or following injury

- Ensuring people have a positive experience of care
- Treating and caring for people in a safe environment and protecting them from avoidable harm

As practitioners and partners at the heart of multidisciplinary teams, CNSs have influence and credibility across the care pathway. They are increasingly taking a leadership role in refining systems and smoothing care pathways, making a demonstrable contribution to effectiveness, patient experience and safety.

Experience from the front line – CNSs transforming cancer care

Improving quality and experience of care

- Managing complex, individual and changing information and support needs of patients and carers
- Supporting patients in choices around treatment and care
- Enhancing recovery and delivering care flexibly and closer to home
- Facilitating set up of support groups

Reinforcing safety

- Delivering safe, nurse-led services
- Using vigilance of symptoms and drug toxicity to trigger rescue work
- Identifying and taking action to reduce risks
- Facilitating rapid re-entry into acute services, if appropriate

Impact of key CNS-led activities

Increasing productivity and efficiency

- Intervening to manage treatment side effects and/or symptom control, preventing unplanned admissions
- Providing nurse-led services that free up consultant resource
- Empowering patients to self-manage their condition

Demonstrating leadership

- Educating the wider healthcare team and acting as a mentor
- Identifying and implementing service improvement and efficiencies
- Determining measurable outcomes, auditing practice, and sharing good practice and innovation

CNSs across the country are already transforming patients' experiences of cancer care. The following case studies provide a flavour of the kinds of initiatives

that CNSs are leading – highlighting their pivotal role in maximising resource and benefitting patients.

Case Studies



Innovation, project management, change management

Lesley Barnett, Macmillan Lead Cancer Nurse, Doncaster
Gina Wibberley, Macmillan Lung CNS, Lincoln

CNSs in Doncaster and Lincolnshire have implemented rapid alert systems to ensure that they are immediately informed when one of their patients enters hospital with an unplanned admission. Using mobile technology and integrated IT systems, a text message and email is sent to the CNS who can immediately attend the patient or discuss the case with the treating clinicians.

Using their specialist knowledge in lung cancer, and their understanding of individual patients' needs, CNSs in Lincolnshire use this as an opportunity to re-assess the patient's cancer pathway outside of scheduled patient planning, or identify where a quick specialist intervention can turn around an inappropriate admission. The nurses in Doncaster have identified

length-of-stay reductions of one to two days per patient, they work to ensure that the patient is admitted to the correct ward and in some cases prevent admission altogether. Added to these productivity benefits is the increased quality of care experienced by patients who report feeling completely supported, knowing that they are receiving coordinated care.

Empathy for patients and their families

Frances McKay, Macmillan Mesothelioma and Lung CNS, Medway

Frances, and her colleagues Caroline Williams and Pat Cameron, run the only lung cancer and mesothelioma support group in their Cancer Network. Up to 28 people each month attend the group.

The CNSs work in collaboration with a local hospice to facilitate the

monthly group meetings with a hospice volunteer managing the meeting practicalities. A successful buddy system has been established for patients and carers who face the challenging and complex issues of a terminal disease.

The group also enables the CNSs to identify emerging health issues,

including helping patients to self-manage symptoms such as shortness of breath, reducing anxiety and maintaining quality of life. Importantly, the CNSs are able to mediate between patients and hospital services and quickly address any issues of concern raised by patients and their families.



Advanced clinical and diagnostic skills

Sharon McGeary and Amanda Gerrard, Paediatric Oncology Outreach Network CNSs, Newcastle Upon Tyne

Nurses from the children's oncology outreach service in Newcastle work with children and young people throughout their cancer journeys. Using specialist knowledge of symptom management, palliative and complex care, the nurses work a 24/7 on-call system, allowing for timely, effective interventions which maximise care delivery. The nurse team are trained as non-medical prescribers, and more than half are practising prescribers.

Working in a large geographical region, the nurses have developed effective collaborative working practices with local primary care service providers. This is particularly important in enabling children and young people with progressive disease to be cared for, and die, in their preferred place of choice, often their home.

The nurses are leading the way in the implementation of new technologies in their hospital trust. "Smart Pump" technology,

considered to be the next generation of ambulatory infusion devices, allows the release of medication over seven days - maximising symptom management and minimising hospital attendance. Corresponding drug libraries, managed by the nurses, help to improve safety by reducing drug errors, improving workflow and providing a new source of data for continuous quality improvement.



Acting as key worker across the whole care pathway

Tina Lightfoot, Lead Specialist Nurse for GI services (surgery), Chester

Tina and the colorectal specialist nurses provide quality services to enhance recovery for patients with colorectal cancer at the Countess of Chester Hospital. Through a pre-operative counselling initiative, patients and carers have an increased understanding of recovery and discharge expectations, helping

them to make plans for managing care at home. In addition, patients who are expected to have a stoma are visited at home by the stoma nurse for a 'dummy' teaching session, reducing the time it takes to become self-sufficient in stoma management.

Patients on the enhanced recovery programme are discharged as early as two days after surgery, and

there is evidence that this is significantly reducing care costs. The colorectal specialist nurses contact the patient daily after discharge for up to 10 days to assess their progress. This vigilance ensures that complications are picked up early enabling timely intervention, and patients report feeling supported through their recovery.



Excellent decision making abilities

Debbie Fitzgerald, Gynaecology CNS, Torbay

Debbie has developed an innovative early-alert service for women with ovarian cancer who suffer from a painful and distressing build up of fluid in the abdominal area.

Patients are alerted to the possibility of fluid build-up, and encouraged to phone her if they begin to experience symptoms. When contacted, Debbie makes a clinical assessment, organising an abdominal scan if required and booking blood tests pre-admission. The drainage can then be done as a day patient, preventing emergency

admission to A&E and lengthy inpatient stays as well as improving patients' quality of life.

The CNS's coordinating role ensures that phlebotomists, radiographers, and the medical team are all available at the right time. Debbie has developed this into a protocol - now widely used.

Advanced communication and advocacy skills

Judith Clarke, Surgical Breast Care CNS, Coventry

Judith has developed an innovative system to monitor and best manage anxiety among patients recalled to the breast screening clinic for further assessment following attendance to the NHS breast screening programme. Judith devised a simple tool that encourages patients to reflect on their anxiety and prompt them to seek

additional support from the breast care nurse (BCN). It also promotes greater collaboration with radiographers and a more coordinated patient-centred experience.

Designed to look like a thermometer, the assessment tool asks women to score themselves from 0-10 (low to high anxiety) enabling BCNs to triage the more

vulnerable women (scoring 5 and above) and ensure they are offered a BCN consultation before being re-screened. Radiographers also use the self-assessment to ensure more patient-focused care, taking into account women's concerns. Feedback from patients shows that women find this activity useful and many have commented on how it helped to reduce their anxiety.

Case Studies (continued)

Demonstrating Leadership

Catherine Oakley, Nurse Consultant, London

Catherine and the team of chemotherapy nurse specialists at Guy's and St Thomas' Hospital have been working together to redesign the way chemotherapy is delivered. Nurses in the chemotherapy unit now work in four specialised teams according to tumour types to improve consistency for patients and maximise the nurses' clinical expertise.

Catherine piloted an intervention in urology in which a specialist nurse and pharmacist delivered an improved pre-treatment consultation. The key to its success is structuring the consultation to ensure that patients' educational and supportive care needs are met to optimise safety and empower patients to actively participate in their treatment plan. Additionally,

CNSs proactively call patients to monitor their progress during the course of their treatment. Closely monitoring patients in this way ensures that any side-effects can be quickly managed and that patients are supported through this sometimes difficult part of their cancer journey.

In-depth knowledge of tumour area

Tessa Fitzpatrick, Macmillan Lung CNS, North Tees

Analysis of patient experience at University Hospital of North Tees suggests that lung cancer patients and carers can encounter problems following admission to the Emergency Assessment Unit (EAU). These include unnecessary investigations, poor symptom management, lack of recognition of end of life, delays in discharge and inadequate communication.

This has a negative impact on patients' confidence in the service and also on the length of stay which has a cost implication.

The CNSs at North Tees use their specialist knowledge of lung cancer to support patients who are admitted as emergency cases, reducing inpatient stays and helping patients and carers to

understand and manage symptoms. University Hospital of North Tees examined a total of 94 inpatient episodes resulting in 964 bed days. The average length of stay for those patients not referred to the lung CNS was 10.8 days however there was a reduction in length of stay to 9.7 days for those patients who had lung CNS input during their admission.



Ability to assess patients' holistic needs

Anita Pabla, Sarcoma CNS, Leicester

Anita works with patients throughout their cancer

journey but has particularly focussed on supporting survivorship and smoothing the transition from secondary to primary care.

Six to eight weeks post-treatment, she provides patients with detailed

and individual 'end of treatment' summaries within the context of a holistic consultation. This captures their initial diagnosis and treatment history, medication and follow-up schedule - incorporating the wider services they have accessed, such as limb-fitting and support groups. The summary also acts as an important communication tool for their GP,

enabling greater integration between different parts of the patient pathway.

The summary and assessment has proved valuable to patients - increasing their confidence and ability to self-manage - as well as to primary care - improving appropriate referral if and when needed.

Delivering the future for cancer patients

The NHS White Paper, *Equity and Excellence: Liberating the NHS*, puts patients and clinicians at the heart of decision-making in the NHS. The phrase “no decision about me without me” is used in the White Paper to emphasise patients’ involvement in their own care.¹⁰ CNSs are often the main point of contact for cancer patients and their families, and work closely with colleagues throughout the patient’s cancer journey. As a result, they are well placed to support patients at each stage and to promote integration within care teams.

Equity and Excellence proposes a shift away from measuring clinical inputs and processes in favour of achieving improved clinical outcomes and higher quality patient experience. Here too, CNSs already demonstrate their skills in assessing and putting in place interventions to achieve these.

The Cancer Reform Strategy (2007) stated that: “Commissioners and providers should ensure that the critical roles of clinical nurse specialists in information delivery, communication and coordination of care

are supported”.¹¹ This remains essential to achieving safe and high quality cancer care and we expect to see this reflected in the refreshed Cancer Reform Strategy.

Nursing is changing, reflecting and rewarding the skills and expertise of its workforce. Career pathways have been updated and transferable skills identified to enable nurses to shape their careers within and across different care pathways.¹² Embracing new models of care, the CNS role extends beyond the hospital setting into local community and specialist settings and increasingly includes informed individual care planning that enables patients to self-manage their condition where possible.

There is wide variation in the types of tasks that CNSs are carrying out. While some of these make good use of their skills, there is evidence that CNSs are also being diverted into general ward duties and tied up in administrative tasks. This does not represent good value to the NHS. Commissioners, employers and managers therefore need to consider whether CNSs are being deployed to best effect.

Matching workforce planning to patient need

Clinical teams will be considering whether provision of CNSs in their local area is sufficient to meet need. Understanding the patterns of access is fundamental to being able to match the CNS workforce to patients’ needs. Despite the expansion in overall CNS numbers since the 1980s, workforce shortages are still an issue.¹³

The best available data indicates that not every cancer patient has access to a CNS, despite the recommendations made in the *Improving Outcomes Guidance*. The National Cancer Action Team’s Workforce Review Team 2010 census demonstrates significant variation in provision of cancer

CNSs in England, which cannot be accounted for by geographical differences in cancer incidence or in patient flows.¹⁴ Since the last census in 2008,¹⁵ there appears to have been an increase in CNS posts in rarer cancers, but the 2010 census revealed no significant growth in other tumour groups despite increasing cancer prevalence. Inequities remain across England and also between different tumour types. Patient advocacy groups have argued that in some cancers - notably lung and urological cancers - CNS provision falls significantly short of patient need and that CNSs face variable case-loads.

Issues for Employers and Managers to consider

CNSs provide quality care and contribute to improved outcomes for cancer patients. They lead innovation, and can drive efficiency in their teams. They also contribute to the delivery of health strategies and policy guidance including:

- Cancer Reform Strategy
- Improving Outcomes
- Quality, Innovation, Productivity and Prevention Challenge
- High Impact Actions for nursing and midwifery
- Equity and Excellence: Liberating the NHS
- Chemotherapy Services in England
- Vital Signs
- End of Life Care Strategy

Employers and managers may wish to ask the following questions when considering their cancer services and assessing their CNS provision, to identify to what extent cancer services are configured to maximise the safety, quality and productivity of care:

Your community

- What is the all-age, all-cause cancer incidence rate in your PCT?
- What are the demographics of your PCT in terms of: age; socioeconomic and deprivation factors; prevalence of risk factors; ethnicity?
- Are there communities with particular unmet needs?
- What priority issues for cancer have been identified through the Joint Strategic Needs Assessment?
- How have you reflected these in the selection of local priorities and incentives for health care providers e.g CQUINs? QOF?
- How do you plan to measure and improve outcomes in these areas?

Provision and capacity

- How many whole-time equivalent CNSs posts are there in your PCT?
- What is the distribution of these across different cancers?
- How does this compare to patterns in neighbouring areas and to the national picture?
- Does each specialist team dealing with a particular cancer type have at least one CNS member?
- How good is CNS attendance at MDT meetings for each team?
- How many new patients does each CNS see each year?
- Have you considered using the expertise of the Macmillan Cancer Support Service Development Team to redesign CNS roles and services should you have concerns that CNSs may not be working to the best potential of their roles?

Where can CNSs make most impact?

- How many unplanned admissions are there for cancer each year in your PCT? And how does this vary by cancer type?
- Do audited records demonstrate that at least 80% of patients receive information about their diagnosis, treatment and care plan?
- Can it be demonstrated that care is effectively coordinated across boundaries?
- Are CNSs working in roles that reflect and demand their knowledge and skills or are they undertaking general ward duties?

Further sources of information

- Cancer Commissioning Guidance
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_110115
- Cancer Commissioning Toolkit
<https://www.cancertoolkit.co.uk>
- Cancer Reform Strategy and Annual Reports
<http://www.dh.gov.uk/en/Healthcare/Cancer/ReformStrategy>
- National Cancer Intelligence Network
<http://www.ncin.org.uk>
- Association of Public Health Observatories
<http://www.apho.org.uk/>
- Public Health Observatory Handbook of Health Inequalities Measurement
<http://www.sepho.org.uk/viewResource.aspx?id=9707>
- Guidance on Joint Strategic Needs Assessment
http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081097
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- Department of Health, Equity and excellence: Liberating the NHS, July 2010
http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_117794.pdf
- To download this publication go to:
<http://ncat.nhs.uk/our-work/ensuring-better-treatment/quality-in-nursing>

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Endorsements

The content of this publication is endorsed by the following organisations:



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