

# Seeking consent:

**Working  
with children**

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# Introduction

## Children

For the purposes of this booklet the term children used is consistent with the definition under Children (Northern Ireland) Order 1995. This states at Article 2 that:

“Child .....means a person under the age of 18”.

If your work involves health or social care of any kind with children (in the health or social care context anything from helping a child get dressed to carrying out major surgery, whether in hospital or in the child’s own home), you need to ensure you have consent for your actions. Obtaining such consent before providing care or treatment is both a fundamental part of good practice and a legal requirement. The process for obtaining consent will vary from simple situations such as assistance with dressing, when a question ‘shall I help you’ would suffice if the child is able to understand, to complex situations where a considerable amount of information would be needed to support decision-making.

If children are not legally competent, that is do not ‘have capacity’, to give consent for themselves, you will need consent from someone who has parental responsibility for them, unless it is an emergency and it would be unreasonable to wait. The word “parents” is used throughout this guidance to refer to those with parental responsibility for a child – see page 6 for information on when birth parents do and do not have parental responsibility, and on who else can exercise this responsibility.

The Department of Health Social Services and Public Safety (DHSSPS) guidance, Reference Guide to Consent for Examination, Treatment or Care, sets out in detail the current law on consent and gives references to legal cases and good practice guidance from regulatory bodies. This booklet focuses on the particular issues which may arise when seeking consent from children and their parents. There are separate booklets for those working with older people and people with learning disabilities.

The first part of this booklet sets out:

- whom you should seek consent from;
- when children can consent for themselves;
- when others need to decide on their behalf.

The second part gives guidance on:

- how best to seek consent;
- what you need to take into consideration.

The third section looks at some of the more complex situations which sometimes arise:

- for example, where children and parents cannot agree;
- where consent is being sought for an intervention which will not directly benefit the child, such as donating bone marrow for a sister or brother.

The final section covers treatment for mental disorders.

# Who Can Give Consent?

## Persons aged 18 or over

Persons aged 18 years or over can always give consent for themselves unless they are deemed not competent.

If children are competent to give consent for themselves, you should seek consent directly from them. The legal position regarding 'competence' is different for children aged over and under 16.

## Children aged 16 and 17

Once children reach the age of 16, they are presumed in law to be competent to give consent for themselves for their own surgical, medical, dental treatment or social care, and any associated procedures, such as investigations, anaesthesia, nursing or social care. This means that in many respects they should be treated as adults – for example if a signature is necessary on a consent form, he/she can sign for themselves.

However, it is still good practice for competent children to be encouraged to involve their families in decision-making. Where a competent child does ask you to keep his/her confidence, you must do so, unless you can justify disclosure on the grounds that you have reasonable cause to suspect that the child, or other children are suffering, or are likely to suffer, significant harm. You should however seek to encourage children to involve their family, unless you believe that it is not in their best interests to do so.

## How do you assess competence?

Like adults, children aged 16 and 17 may sometimes not be competent to take particular decisions. For example, they may be unconscious, or be unable to take a decision because of the effects of pain, trauma, fatigue or medication. For young people to have the capacity (be competent) to take a particular decision, they must be able to:

- comprehend and retain information material to the decision, especially as to the consequences of having or not having the intervention in question; and
- use and weigh this information in the decision-making process.

You should never automatically assume that a child with learning disabilities is not competent to take his or her own decisions: many children will be competent if information is presented in an appropriate way and they are supported through the decision-making process. If a child of 16 or 17 is not competent to take a particular decision for him/herself, then a person with parental responsibility can take that decision, although the child should still be involved as much as possible (see page 9). However, once individuals reach the age of 18, **no one** else can take decisions on their behalf. If an 18 year-old is not competent to make his/her own decisions, health and social care professionals can provide treatment and care that is in his/her “best interests”. More information on “best interests” and treating people over 18 who are not competent to consent is given in the Department of Health, Social Services and Public Safety Reference guide to Consent for Examination, Treatment or Care.

## Children aged under 16

Unlike 16 or 17 year olds, children aged under 16 are not automatically presumed to be legally competent to make decisions about their health or social care. However, the courts have stated that a child aged under 16 will be competent to give valid consent to a particular intervention if he/she has “sufficient understanding and intelligence to enable him or her to understand fully what is proposed” (sometimes known as “Gillick competence”). In other words, there is no specific age when a child becomes competent to consent to treatment: it depends both on the child and on the seriousness and complexity of the treatment being proposed.

‘Competence’ is not a simple attribute that a child either possesses or does not possess: much will depend on the relationship and trust between you and your colleagues, and the child and his/her family. You can help children to develop competence by involving them from an early stage in decisions and encouraging them to take an increasing part in the decisions made about their care. This will particularly apply where you are caring for a particular child over a period of time, for example where the child needs a series of operations.

If a child under 16 is competent to consent for himself or herself to a particular intervention, it is still good practice to encourage involvement of their family in decision-making unless the child specifically asks you not to do so. As with older children, you must respect any request from a competent under-16 year old to keep his/her treatment or care confidential, unless you can justify disclosure on the grounds that you have reasonable cause to suspect that the child or other children are suffering, or are likely to suffer, significant harm.

## People with parental responsibility

If a child is not competent to give consent for him/herself, you should seek consent from a person with 'parental responsibility'. This will generally, but not always, be the child's parent. Legally, you only need consent from one person with parental responsibility, although it is necessary to consult the child as well as involving those close to the child in the decision-making process.

The Children (Northern Ireland) Order 1995 and Family Law (Northern Ireland) Act, 2001 sets out who has parental responsibility and these include:

- the child's parents if married to each other at the time of conception or birth;
- for children born before 15/4/02 the child's mother, but not the father if they were not married at the time of the birth unless the father has acquired parental responsibility via a court order or a parental responsibility agreement or the couple subsequently marry;
- for children born to unmarried parents on or after 15/4/02, the child's parents if they jointly registered the child's birth, so that the father's name appears on the birth certificate. When a birth is not jointly registered the child's mother only has parental responsibility, unless the father has acquired parental responsibility via a court order or a parental responsibility agreement or the couple subsequently marry;
- the child's legally appointed guardian – appointed either by a court or by parents with parental responsibility in the event of their own death;
- a person in whose favour a court has made a residence order concerning the child;
- a Health and Social Services Trust designated in a care order or interim care order in respect of the child (this excludes children being looked after under Article 21 of the Children (Northern Ireland), Order 1995 who are 'accommodated' on voluntary basis and for whom a HSS Trust does not have parental responsibility;

- a Health and Social Services Trust or other authorised person who holds an emergency protection order in respect of the child.

Usually foster parents, step-parents, private foster carers and grandparents do not have parental responsibility, unless they have acquired it through a court order.

If a child's mother is herself under 16, she will only be able to give valid consent for her child's treatment if she is deemed competent to take the decision in question (see page 4). Whether or not she is able to give valid consent on behalf of her child may therefore vary, depending on the complexity of the decision to be taken.

If a child is a ward of court, all "important steps" in the child's life must first be approved by the court. If possible it will be helpful to keep copies of the wardship order with the child's medical or social care record, so that it is clear what, if any, intervention may be provided without reference to the court.

While only a person exercising parental responsibility can give consent, persons with parental responsibility can arrange for some or all of that responsibility to be met by others. Parents might, for example, give authority for someone who cares for their child on a regular basis, such as a grandparent, private foster carer or childminder, to give consent for medical treatment and their care under defined circumstances (for example in emergencies or for routine treatments for coughs and colds). Where such explicit authority has been given, the consent of the person so authorized will be valid and you will not need to try to contact those with parental responsibility as well, unless you have reason to believe that the parent's view might differ. The Children (Northern Ireland) Order (Article 5(8)) does not require that such authority should be given in writing, but clearly it is helpful for health and social care workers if it is. Where a child with complex health or social care needs is regularly cared for away from home (for example if they attend a residential school), it will be good practice for a care plan to be agreed between the child, the parents, and the health or social care professionals regularly involved in caring for the child. This will enable any significant differences of opinion to be identified and resolved in advance, rather than under pressure in an emergency situation.

The Children (Northern Ireland) Order also allows a person who does not have parental responsibility for a child but who 'has care' of a child to 'do what is reasonable in all the circumstances of the case for the

purpose of safeguarding or promoting the child's welfare'. This might apply, for example, to childminders, private foster carers or teachers, where explicit authority to consent on behalf of a child has not been given by the person with parental responsibility. However, it would rarely be 'reasonable' for those with care of a child to consent to treatment on the child's behalf if a parent could be contacted instead. In an emergency, it would certainly be reasonable for a teacher, private foster carer or childminder to take a child for appropriate medical care, which could then be lawfully provided on the basis that the care was in the child's best interests and no one with parental responsibility could be contacted (see page 13).

Where a person exercising parental responsibility is giving consent for a child's treatment or care, it is important that they have the necessary information both about the proposed procedure and the child, in order to take a proper view as to the child's best interests. This may be particularly relevant if consent is being given by a person with parental responsibility who does not have day-to-day care of the child.

## **Making sure children are involved in decision-making**

Even where children are not able to give consent for themselves, it is very important to involve them as much as possible in decisions about their own health and care. Even very young children will have opinions about their health and care, and you should use methods appropriate to their age and understanding to enable these views to be taken into account. A child who is unable to understand any aspects of the health or care decision may still be able to express preferences about who goes with him/her or what toys or comforters he/she would like to have with them. Similarly, where treatment or care choices involve multiple decisions, children may be able to give their consent to some aspects of their care, even where they are not able to make a decision on the treatment or care as a whole.

Parents will often be unsure about how much information they want their child to have (particularly when a young child is seriously ill), and you will need to discuss this sensitively with them.

Decision-making with older children will often be a matter of negotiation between the child, those with parental responsibility and health and social care professionals: children should never feel that decisions are being made over their heads.

# How Do I Go About Seeking Consent?

The first part of this booklet summarised who can lawfully give consent for a child's treatment or care. This section looks at some of the issues which arise when seeking consent. References to "parents" includes others with parental responsibility for the child.

## Is the consent valid?

For consent to be valid, the person (child or parent) giving consent must be:

- capable of taking that particular decision ('competent');
- acting voluntarily (not under pressure or duress from anyone);
- provided with enough information to enable them to make the decision.

Guidance on how to assess if the person giving consent is capable of taking that decision is given on pages 4-5. See page 13 for advice if neither the child nor anyone with parental responsibility is in a position to give valid consent.

## What information do children and their parents need?

Children and their parents clearly need enough information before they can decide whether to consent to, or refuse, treatment or services. In particular, they need information about:

- the benefits and the risks of the proposed intervention;
- what the intervention will involve;
- what the implications of not having the intervention are;
- what alternatives may be available;
- what the practical effects on their lives of having, or not having, the intervention will be.

It is essential that this information is provided in a form that is understandable, and that you check the child's understanding. This will involve explaining what is proposed in language which is suited to the child's age and abilities, using pictures, toys and play activity where appropriate and drawing on the skills of specialist colleagues. Except in an emergency, information should be provided at the child's own pace, allowing time and opportunity to take and answer questions and to address concerns, fears and expectations.

It may also involve using interpreters, where the child's, or their parents' first language is not English. If an interpreter is available, you should avoid asking the child or any family member to interpret for the child's parents.

Where a child has a disability, particular care should be taken to ensure that the information is provided in a suitable form, involving, for example, interpreters for hearing impaired children or appropriate materials for those with learning disabilities. Specialist colleagues may be able to act as facilitators or advocates where children have particular needs.

## The process of seeking consent

Sometimes you will have to seek consent urgently, for example if a child has had a road accident and immediate surgery is necessary. However, where treatment or care is not immediately necessary, seeking consent should usually be seen as a process, not a one-off event. For example, if a tonsillectomy is suggested, seeking consent does not simply consist in asking for a signature just before the operation takes place. Rather, the whole process of discussing options and coming to a decision should be seen as part of the consent process. Information about the risks of treatment or care should be discussed early on in this process, and not presented at the last minute when it is too late for it to be considered properly.

Children and their parents who have given consent to a particular intervention are entitled to change their minds and withdraw their consent at any point. However, if you have started a procedure, such as an operation under local anaesthetic, and it would be dangerous to stop at that point, it would be lawful to continue until any risk to the child is over. Withdrawal of consent in such circumstances may reflect fear or pain, rather than genuine refusal, and you should do all you can to reassure the child and/or his/her parents.

Sometimes, during an operation, it may become clear that the child would benefit from an additional procedure, for which consent has not been obtained. You **must** obtain further consent for this procedure before going ahead, unless the delay involved in doing so would genuinely put the child's life or health at risk.

## Consent forms

Legally, it makes no difference whether a consent form is signed, or whether consent is given verbally or even non-verbally (for example by holding out an arm for blood pressure to be taken). A consent form is only a record, not proof that genuine consent has been given. It is good practice to seek written consent if treatment or care is complex, or involves significant risks or implications for the life of the child and his/her family. Where children are competent to give consent for themselves (see pages 3-5), their signature on a consent form is sufficient without the need for their parents to counter-sign it. If parents have been involved in the decision, however, it may be appropriate for both the child and his/her parent to sign to indicate their joint involvement in the process.

## More Complex Situations

### Where no one is able to give a valid consent

Sometimes there may be no one able to give valid consent to treatment. This might be because a child is unconscious after an accident, needs treatment urgently, and no-one with parental responsibility can be contacted. It may also be because the child is homeless or is an unaccompanied refugee, and does not have the capacity to give consent for himself or herself. In such circumstances, it is lawful to provide immediately necessary treatment on the basis that it is in the child's best interests.

Sometimes, the person with parental responsibility may be available, but is not competent to give or withhold consent: for example if the person with parental responsibility is under the influence of drugs, or the mother of a child is herself under 16 and is not competent to make that particular decision (see page 5). In such cases, if there is no-one else with parental responsibility available and the treatment cannot wait, it will be lawful to provide it on the basis that it is in the child's best interests.

Another scenario might be where the parents of a seriously ill child are not competent to give valid consent because of extreme distress. If it is genuinely not possible to delay treatment until the parents are in a position to make a decision, treatment may lawfully be started if clinicians believe it to be in the child's best interests. However, all attempts must be made to ensure that as soon as the parents are able to make a decision, their consent to further treatment is sought.

## Where health and social care professionals and those with parental responsibility do not agree

Health and social care professionals and parents will not always agree on what is best for a child. Usually, when parents refuse treatment or care for their child, this will prevent the proposed action going ahead. However, if you and your colleagues believe that it is crucial for the child to have the treatment or care in question (for example if the child would die, or suffer serious permanent injury without it or would suffer or be likely to suffer significant harm), then the courts can be asked to decide what is in the child's best interests. Applications to court can be made at short notice if necessary<sup>1</sup>. If the emergency is such that there is no time to apply to court, any doubts should be resolved in favour of the preservation of life.

Sometimes, the opposite situation will arise: where health and social care professionals believe that treatment or care which the parents want is not appropriate. One example would be where a child is very seriously ill, and clinicians believe that the suffering involved in further treatment would outweigh the possible benefits. Parents cannot require you to provide a particular treatment if you do not believe that it is clinically appropriate, but again the courts can be asked to **rule** if agreement cannot be reached. While a court would not require you to provide treatment against your clinical judgement, it could require you to transfer responsibility for the child's care to another clinician who does believe that the proposed treatment is appropriate. Further guidance on withholding and withdrawing life-sustaining treatment is given in the Department of Health, Social Services and Public Safety Reference Guide to Consent for Examination, Treatment or Care (2003), the BMA guidance *Withholding and withdrawing life prolonging medical treatment* (2001) and the Royal College of Paediatrics and Child Health guidance *Withholding or withdrawing life saving treatment in children: a framework for practice* (1997).

<sup>1</sup> This should be done through the legal department of the HPSS body involved

## Where parents do not agree with each other

The consent of any one person with parental responsibility is sufficient for treatment or care lawfully to be given, even if another person with parental responsibility does not agree. For example, treatment or care could lawfully be given with the consent of the Health and Social Services Trust where a child is on a care order, even if the child's mother did not agree. Clearly consensus between those with parental responsibility should be achieved if at all possible.

In addition, the courts have said that a small number of "important decisions" should not be taken by one person with parental responsibility against the wishes of another, citing in particular non-therapeutic male circumcision. It is possible that major experimental treatment, where clinical opinion is divided, might also come into this category, although such a case has not yet come to court.

## Where children and those with parental responsibility do not agree

Inevitably there will be times when children and those with parental responsibility for them do not agree on whether the child should have a particular intervention or treatment.

The decision of a competent child to **accept** treatment cannot be over-riden by a person with parental responsibility. However the courts have said that, exceptionally, if the child **refuses** treatment, those with parental responsibility may consent on his/her behalf, and treatment can lawfully be given. This power to over-rule a competent child's refusal should be used very rarely, bearing in mind both the consequences of forcing treatment on a child who has refused it and the consequences of non-treatment in this particular case. At all times you should be guided by the **best interests** of the child.

Where a child is refusing treatment which his or her parents want to accept, and the consequences of refusal are potentially very serious (for example the foreseeable death of the child), consideration should be given to seeking a court ruling on what would be in the best interests of the child. Courts have the power to over-rule the decisions of both children and those with parental responsibility. Where the consequences are less serious, you should do all you can to help the child and his/her parents reach agreement.

Similarly, there may be differences of opinion between parents and children who are not deemed competent. While, legally, the consent of the person with parental responsibility is sufficient for health and social care professionals to proceed, it is clearly good practice to do everything possible to reach agreement. In many cases, it may be possible to delay treatment until the child is content for it to go ahead. Again, you should always be guided by the child's best interests.

## **Interventions which do not physically benefit the child**

Occasionally, a procedure may be suggested that will not physically benefit the particular child: for example using a child as a bone marrow donor for a sibling. If the child is competent, then clearly he/she should make up his/her own mind as to whether or not he/she wishes to donate. (It should be noted that the presumption that 16 and 17 year olds are competent only applies to therapeutic treatment, and hence would not cover blood or bone marrow donation. The "test" for competence in such cases is the same as for under 16s: whether the child has "sufficient understanding and intelligence to enable him or her to understand fully what is proposed".)

Where children are not competent to decide for themselves, then those with parental responsibility can consent on their behalf, but only if the intervention is in the best interests of the child who will be undergoing the non-therapeutic intervention. It is not lawful to balance the interests of the child in need of the transplant with the interests of the potential child donor. It will clearly be very difficult for the parents of a seriously ill child to take a dispassionate view of the best interests of the child's healthy sibling. It is therefore good practice to provide independent scrutiny of the parents' decision, for example through an independent assessor or consideration of the case in a hospital clinical ethics committee. If there is any doubt as to the best interests of the healthy child, a court ruling should be sought.

If there is any question of a child donating a solid organ (as opposed to regenerative tissue like bone marrow), then the courts have stated that it is good practice for the courts to be asked to rule in advance – even where the child is competent to make the decision and has expressed his or her willingness to donate.

## Consent to treatment for mental disorder

The same principles which are used when seeking consent for the treatment of children's physical disorders apply when children are suffering from a mental disorder. However, in addition to the legal and good practice principles outlined earlier in this guidance, additional legal provisions for the treatment of mental disorder exist in the form of the Mental Health (Northern Ireland) Order 1986.

Wherever possible, a child should receive treatment for his/her mental disorder on a consensual basis: either with the child's own consent (where the child is competent to give it) or with consent from a person with parental responsibility and the co-operation of the child (where the child lacks capacity in relation to the decision in question). This is most likely to be achieved where you have been able to develop a trusting relationship with the child, and where the child knows that his/her views are being taken into account, even if you are not always able to agree with them.

Where consensus cannot be reached, and you have no doubt that the proposed treatment is in the child's best interests, careful thought must be given as to the most appropriate legal framework to use. While treatment may lawfully be provided with the consent of a person with parental responsibility until the child reaches the age of 18, the implications of ignoring a child's refusal must be considered. The alternative legal frameworks each have their own advantages and disadvantages: the Children (Northern Ireland) Order 1995 allows for court involvement in individual treatment decisions and tends to be perceived as less stigmatising than the Mental Health (Northern Ireland) Order 1986; the Mental Health (Northern Ireland) Order 1986 has in the past been perceived as stigmatising but provides significant safeguards for the child.

As a general principle, care and treatment should be provided in the least restrictive setting which is possible in the circumstances and should involve the least possible disruption in the child's ordinary home and school life.

This guidance can only touch briefly on the particular issues raised by consent to treatment for mental disorders. More specialist guidance should be consulted in these cases.

## Examples

A number of examples are given to illustrate the general principles of consent. They are not intended to provide guidance on specific cases but to enable you to assess how the issue of consent may affect your work with children. Consent **MUST** be assessed on an individual basis.

### Example 1

Before taking a class of 12 year-olds on a week-long school holiday, their school seeks explicit agreement in advance from the children's parents that the teachers in charge may consent to any treatment which becomes immediately necessary during the week. Part way through the holiday, Jonathan suffers from a bad asthma attack in the middle of the night and is quite unable to communicate. However, the teacher taking him to A&E is able to consent on his behalf to nebuliser treatment. The task of the staff in the A&E is made much easier because the teacher bringing Jonathan has clear evidence that she has his parents' authority to exercise parental responsibility if necessary. This avoids the necessity of trying to track down Jonathan's parents urgently by phone before the treatment is given. However, all reasonable action should be taken to contact his parents as soon as possible so that they can be appropriately involved in any follow-up care.

### Example 2

Irene is 13 and goes on her own to see the school nurse about a vaginal discharge. In response to gentle questioning she reveals that her stepfather has been sexually abusing her for the past four years. Irene is competent to consent for herself to the treatment of the discharge and wishes to keep the consultation confidential as she does not wish to upset her mother. However she clearly wishes the abuse to stop. After listening to Irene talk about her experiences, the school nurse sympathetically explains to her that in view of the harm that Irene is suffering, she must involve the child protection team in order to help stop the abuse. The school nurse helps Irene to understand that this is the best and safest thing to do in the circumstances and reassures Irene that she will continue to offer her support during the process.

### Example 3

Sara, aged 15, wants to accept immunization as part of the school immunization programme, but her mother has contacted her school to refuse consent. The school nurse discusses the benefits and risks of immunisation with Sara and forms the view that Sara is mature enough to understand the implications of having the immunisation. The nurse phones Sara's mother to try to explain that Sara is legally able to consent for herself and that having discussed the risks and benefits she wishes to go ahead. Sara's mother finally accepts that her daughter is able to make up her own mind. Even without the final agreement of Sara's mother, the immunisation could lawfully have been given, but the nurse was anxious to achieve consensus wherever possible.

### Example 4

David, aged 14, refuses chemotherapy which his parents wish him to accept. In many ways he seems to be competent to make up his own mind on this decision: he appears to understand the implications of refusing chemotherapy and explains very coherently his concerns about the associated risks of severe nausea and his hair falling out. However, it is clear that he believes that he will 'pull through somehow anyway' without treatment. The clinicians treating him feel it would be very unwise to treat him on the basis of his parents' consent alone, both because it would betray the trusting relationship which has developed between him and those treating him, and because it would be very hard for him psychologically to accept enforced treatment. They are, however, very concerned at the implications for his health if they were to accept his refusal. It is agreed that a court should be asked to decide what is in his 'best interests' so that there is opportunity for all arguments to be discussed openly. The court decides that David should have the treatment. David is able to accept this decision as he no longer feels that those directly involved with him (his parents and the clinicians caring for him) have personally enforced their views on him.

## Example 5

Brian attends a Respite Centre at weekends. He is 12 years of age and has severe cerebral palsy. Brian requires the support of the centre's staff to meet his personal care needs. This includes washing and changing pads. Brian is unable to give consent for the performance of such aspects of care. However, a care plan has been agreed with Brian's parents, outlining his normal routine and identifying how these procedures will be carried out, in keeping with the centre's intimate care policy. This document has been signed by his parents, and a copy is kept in his notes. Brian knows the care workers well, and is most relaxed with his key team. Where possible, key team members attend to his personal care needs, explaining to Brian what they are doing and ensuring his comfort and privacy throughout the procedure.

## Further Sources Of Guidance And Information

Department of Health Social Services and Public Safety, Reference Guide to Consent for Examination, Treatment or Care available at [www.dhsspsni.gov.uk](http://www.dhsspsni.gov.uk)

Royal College of Paediatricians: Good Medical Practice in Paediatrics and Child Health, Duties and Responsibilities of Paediatricians (2002) available at [www.rcpch.ac.uk](http://www.rcpch.ac.uk)

British Medical Association: Consent, rights and choices in health care for children and young people. BMJ 2001 ISBN 0-729-1228-3 ([www.bmjpg.com/consent](http://www.bmjpg.com/consent))

Alderson P and Montgomery J, Health care choices: making decisions with children (1996) IPPR: London

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