



National Network of Parent Carer Forums
'Our Strength Is Our Shared Experience'

Co-production, campaigning & the independence of Parent Carer Forums

A Contact and NNPCF webinar presented by

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Welcome!

Welcome to this Contact and NNPCF webinar.

If there is a technical glitch, please do bear with us.

Those of you joining by PC, laptop, tablet or smartphone should now be able to see this introduction slide.

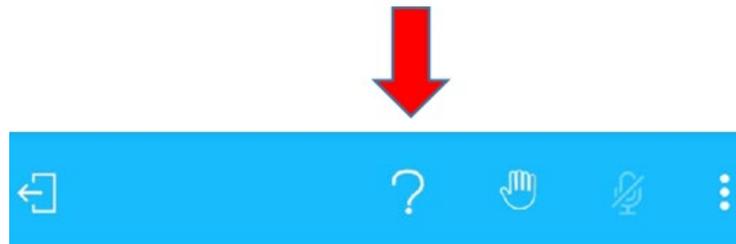


Timings and Questions

As there are so many attendees, it is not practical for verbal questions to be taken, therefore you will all remain 'muted' throughout.

If at any point you have questions, please use the question icon on the GoToWebinar tool bar on your screen, this will allow you to type your question in to the text box and submit this to the Webinar administrator.

We will select as many relevant questions to answer as time allows, if similar questions are received, we will combine these where possible.



Q & A

Further relevant questions, not covered in the time allowed, will be answered and posted on Contact's website along with the recording of the Webinar, details of which will be circulated in the next couple of weeks.

At the end of the Webinar a short questionnaire will launch, please take the time to complete this as it will assist us with planning future online training events.



Definitions

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Charity Commission's definition of campaigning:

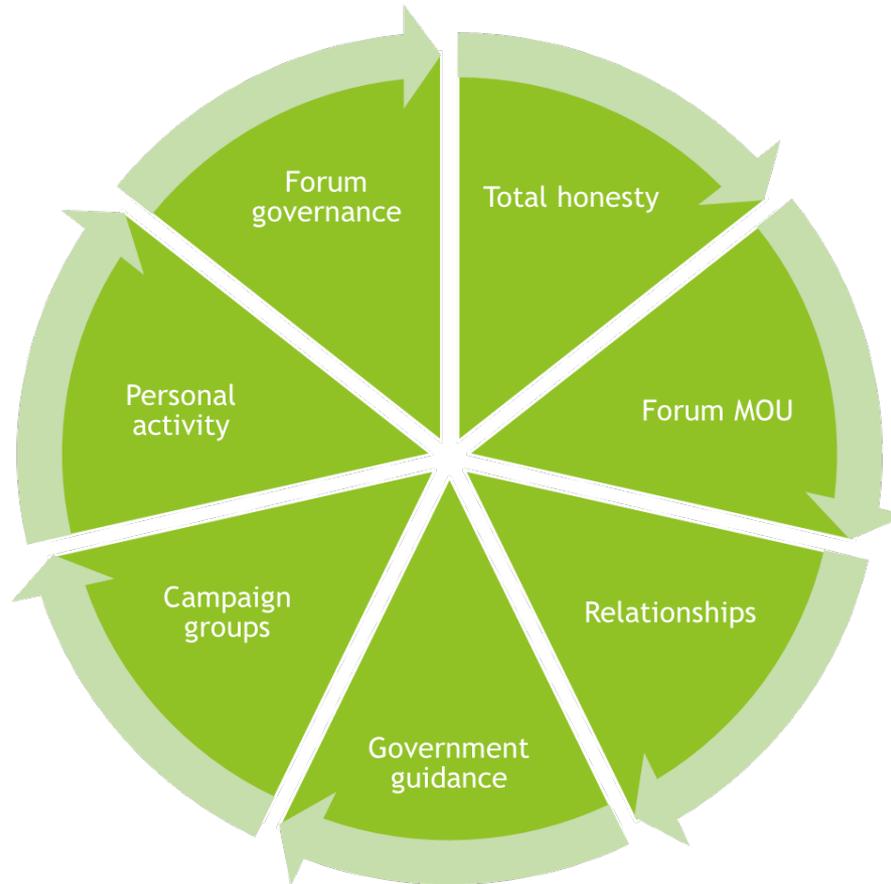
The commission uses this word to refer to “awareness-raising and to educate or involve the public by mobilising their support on a particular issue, or to influence or change public attitudes”. It also uses it to refer to “campaigning activity which aims to ensure that existing laws are observed”.

NNPCF's definition of co-production:

“An equal and reciprocal partnership where everyone's experience, knowledge and skills are used to create better outcomes”



Overview

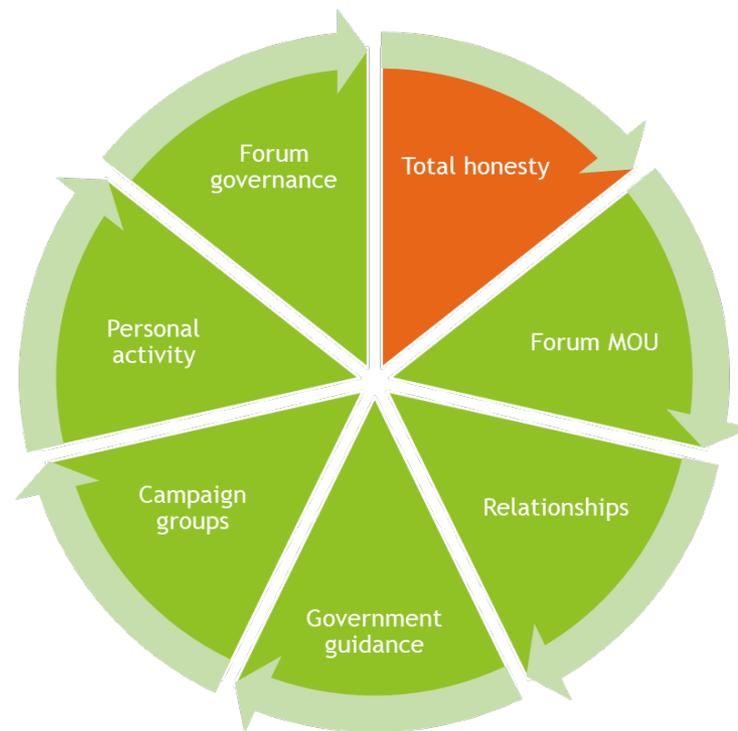


Total honesty

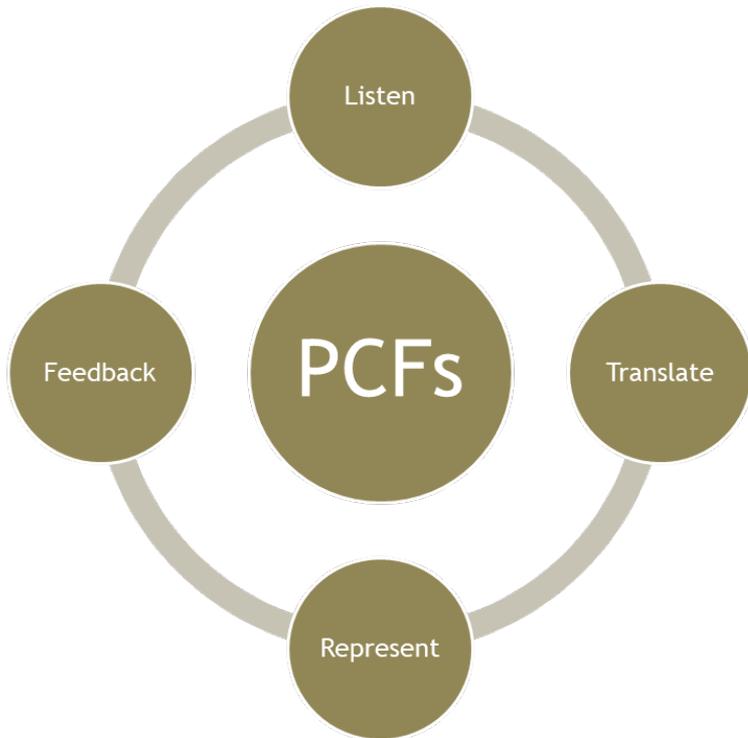
- ▶ Parent carer forums are there to represent their communities.
- ▶ This means we have an obligation to “tell truth to power”.

This includes:

- ▶ Challenging
 - ▶ Criticising (but be constructive)
 - ▶ Evidencing
 - ▶ Holding to account
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- ▶ *Change only happens if you are brutally honest about where you are and relentlessly optimistic about where you want to get to.*



What is the role of parent carer forums?



- ▶ Pulling together the lived experiences of families in a collective overview
- ▶ At the NNPCF we talk about our role as being 4 simple things:

1. Listen
2. Translate
3. Represent
4. Feedback



Be clear about how you listen

- Meetings and events
- Member surveys
- Consultations and calls for evidence
- Social media
- One to one conversations
- Your conference
- Your own lives



Feedback



Forums are not always great at feeding back to our members for various reasons:

- ▶ “We are too busy doing the work”
- ▶ “We don’t like to blow our own trumpet”
- ▶ Forums only communicate when something is finished
- ▶ Forums communicate process (we attended xx meetings last month)

Any communication is good, but:

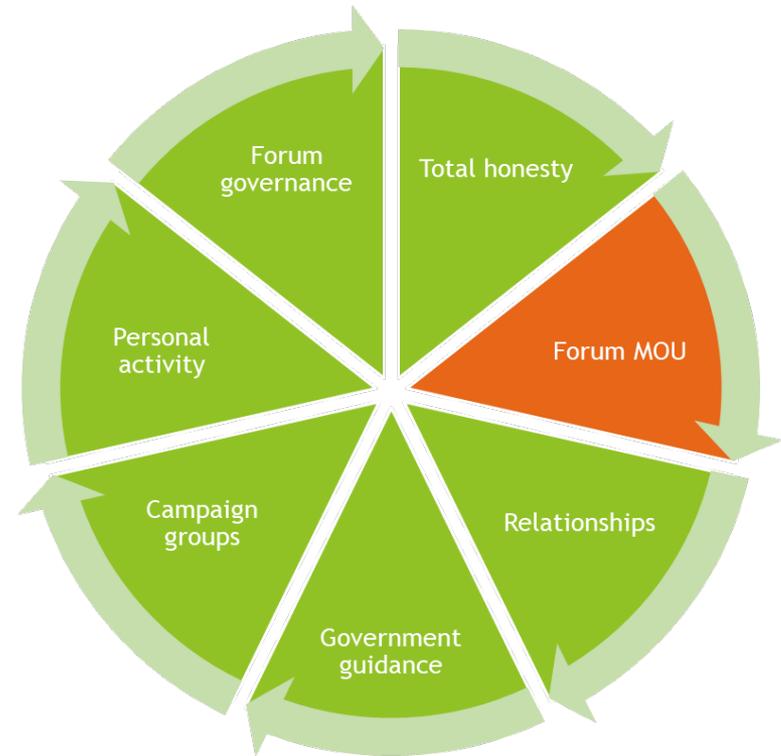
- ▶ What forums really need to communicate is *what* they are saying on behalf of their members.
- ▶ Tell people that you have understood and shared their issues
- ▶ Tell people how you have worked to address those concerns



Forum and local authority MOU (Memorandum of Understanding)

▶ The MOU between the forum and the local authority on the DfE grant form includes some key points:

- ▶ Co-production
- ▶ Independence
- ▶ Respect
- ▶ Honesty



MOU (Memorandum of Understanding) continued...

The MOU was introduced in 2019-20 as part of the DfE grant process and worked well. Forums and LAs committed to:

- ▶ co-produce with the local parent carer forum as described in the SEND Code of Practice.
- ▶ recognise the independence of the parent carer forum.
- ▶ value the role of the parent carer forum in representing the needs, experiences and views of parent carers of children and young people with SEND including their role in raising issues, providing constrictive criticism and holding partners to account.
- ▶ to work together with respect and as equal partners.



The unique role of PCFs



Parent carer forums are embedded in the code of practice



PCFs do the *real* work that makes the system better (e.g. writing policies, reviewing EHCPS, sitting on panels, attending decision making board)



Other recent guidance has also explicitly required Local Authorities to work with PCFs

Additional schools capital funding decisions
Local area inspections guidance (esp. revisit guidance)
Transport consultations



There are additional opportunities to embed PCFs in the system coming up:

Revision of the code of practice 2020
New Local Area inspections guidance post 2021



However, more needs to be done to enforce these requirements



The unique role of PCFs

We are the only parent-carer group that is mandated to be truly representative (many others are condition specific and other rely too heavily on social media)

We are the only group that regards telling people what the issues are as the *start* of the conversation - we carry on and work with stakeholders to make things better.

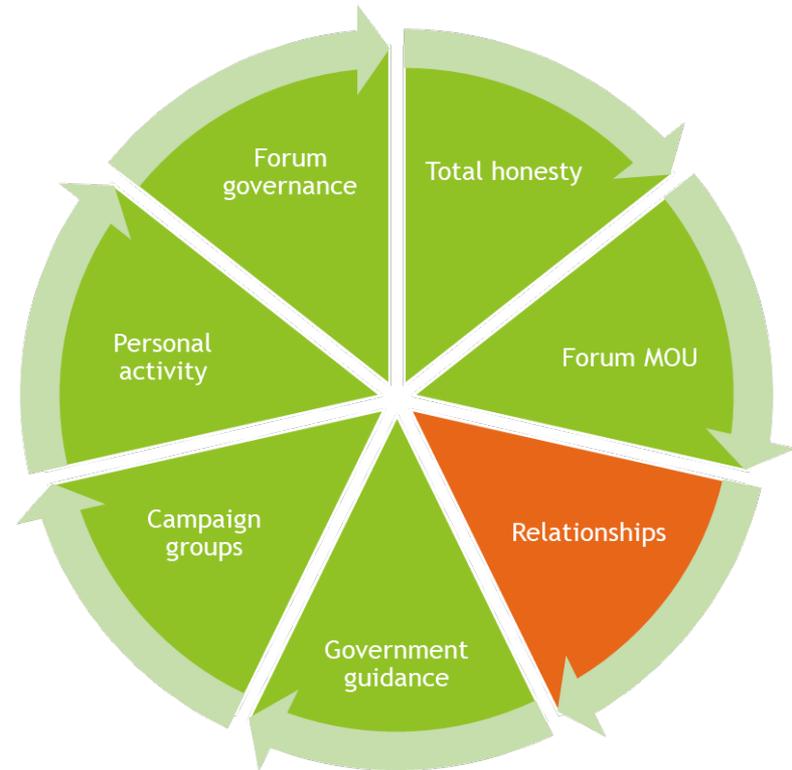


Relationships

- ▶ It takes years to build a relationship, moments to break one.
- ▶ Some guidance
 - ▶ Don't say anything in public that you haven't already said privately
 - ▶ Be respectful
 - ▶ Be factual
 - ▶ Use anecdotes to illustrate points
 - ▶ No surprises

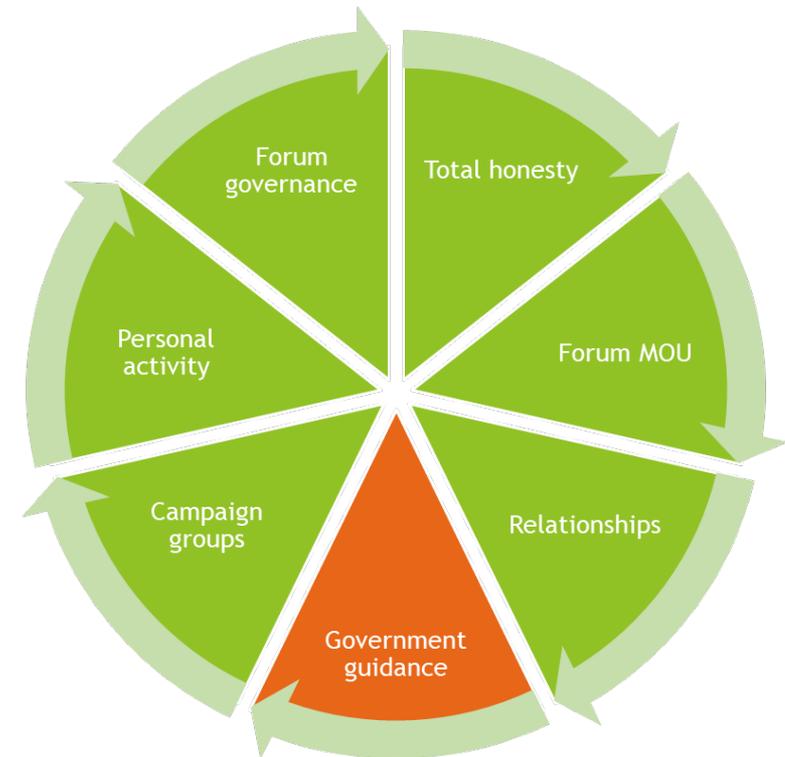
The golden rule

"Treat others as you would like them to treat you."



Government guidance

- ▶ Since February 2016, there have been limitations on use of government funds for campaign activity. This is written into government contracts.
- ▶ Funds from non-governmental contracts are not subject to the same restrictions.
- ▶ But you need to decide whether a particular campaign activity is compatible with your ethos of co-production.



Government guidance

Letter from the Prime Minister to NCVO (National Council for Voluntary Organisations) December 2018



10 DOWNING STREET
LONDON SW1A 2AA

https://www.ncvo.org.uk/images/documents/about_us/media-centre/SIR_STUART_ETHERINGTON_001.pdf

- ▶ “the Government recognises the importance of the voice of charities and social enterprises in speaking out...contributing their valuable insights and expertise to the development of government policy.”
- ▶ “...it is vital that the sector’s independence and freedom of speech are protected...”
- ▶ “...Government contracts do include provisions to ensure that providers adhere to the high standards we expect...”
- ▶ “...these clauses are in no way ‘gagging clauses’”
- ▶ “They do not stop providers...fairly criticising...”
- ▶ “...they do not stop charities from campaigning for a particular cause and would never be used as a means of attempting to stifle legitimate debate...”



Campaign groups

- ▶ There is no restriction on working with campaign groups.
- ▶ Forums can work with local and national campaign groups when their aims and objectives align.
- ▶ Campaign groups can do things that parent carer forums can't:
 - ▶ Protests
 - ▶ Petitions
 - ▶ Using the courts
 - ▶ Media campaigns

Guidance for forums can be found here

<https://contact.org.uk/get-involved/parent-carer-participation/setting-up-and-running-a-forum/>



Herts Parent Carer Involvement & the Nascot Lawn campaign



The Issue

- In June 2017 one of the two CCGs announced closing Nascot Lawn (overnight respite centre for families of children with complex health needs).
- Huge stress and anxiety for families whose children attended the centre.
- Parent carers had not been consulted
- The impact on families using the service and how their needs would be met not assessed
- No proper consultation with other strategic partners (e.g. the other CCG in Hertfordshire LA and parent carer forum)
- Insufficient assessment of impact on other families, services and budgets for parents of children with complex health needs in the future.



What did forum do?

- Forum mobilised quickly and dedicated 2 reps to work with the campaign group and keep their membership informed
- Gave out clear information about the campaign, how parents could be involved/ have their voice heard while being clear on their independent role
- Helped facilitate wider consultation on impact closure would have; & on provision for families of children with complex health needs in county
- Represented views of parents at strategic meetings e.g. scrutiny meetings and helped councillors understand the impact of on families and other services.
- Clearly communicated findings and how they were working with partners to find a way forward to ensure the specific needs of these children were met alongside the needs of all children with additional needs in the county



What were Main Challenges?

- A high profile and complex legal case
- Helping ensure parents understand procedures and processes so their energies were directed in most effective way
- Capacity
- Maintaining a countywide and pan disability role
- Representing these children a small but important group alongside the needs of other children
- Working with a range of partners and groups



What Difference did having the Forum involved make?

- Although the LA recognised the forum as valuable partner throughout this was a high profile case & highlighted the need for proposals like this to be considered jointly between CCGs & the LA with & rigorous consultation & parental input.
- Forum identified gaps in provision e.g. EHCP plans for young children attending the centres
- Working at countywide strategic level meant forum was able to highlight other related issues & identify other services that were needed or would be impacted e.g. the impact of lack of specialist school places on other provision / lack of provision for children under 5 / young people with health needs, lack of access to EHCP plans
- Facilitated discussions with all partners to find a way through the crisis and to find new solutions



- Ultimately the decision was made to close the centre | Forum are now fully involved in ongoing discussions around improving provision for children with complex healthcare needs across health, education & social care
- Meeting with parents directly (& meeting their children) helped councillors fully understand the complexity of these children's needs & the importance of high quality medical care & regular breaks.
- The forum & campaign group working together provided evidence that supported the High Court ruling which recognised that short break services such as those offered at Nascot Lawn are indeed a health service & therefore the NHS has a role to play in funding this type of provision.



Working with campaign groups

- ▶ Tell them what you are saying in meetings with decision makers.
 - ▶ Be transparent about what you can and cannot share.
 - ▶ Explain how this is based on what PCFs are hearing and make sure they understand you are being brutally honest and coproducing to find way forward.
- ▶ Share information about the impact of planned changes to services based on PCF data.
 - ▶ E.g. these changes to transport policy will mean that 52 children spend an extra 30 minutes on the bus.
 - ▶ Don't share anything that is confidential.
- ▶ Share campaign group information on social media (making clear you are just sharing information, not endorsing the action).
- ▶ Compare notes and discuss tactics.
- ▶ Discuss whether some shared legal training on the campaign topic would be useful. The DfE grant can be used to support legal training.



Contact campaigns and forums together

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- ▶ Contact campaigns on topics that matter to local parent carer forums e.g. Universal Credit for disabled young people in education, school transport, more funding for social care
- ▶ Using evidence and experiences from local parent carer forums strengthens our campaigns and conversations with MPs, officials and journalists
- ▶ Get updates on Contacts campaigns at www.contact.org.uk or email una.summerson@contact.org.uk
- ▶ Contact also runs the Disabled Children's Partnership, join at <https://support.disabledchildrenspartnership.org.uk/>



Coproduction **vs** campaigning

You don't represent me!

You're in the local authority's pocket!

- Show how you are listening
- Be transparent about what you are saying and doing (feedback!)
- Ask what they would like you to say that you are not already saying

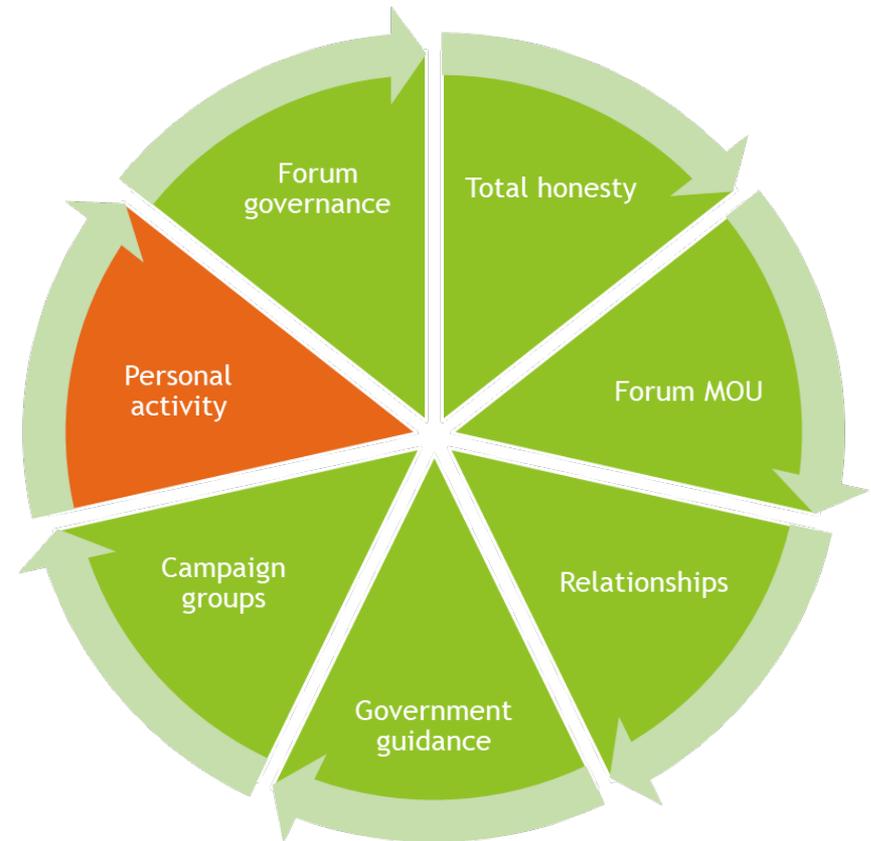
Whose side are you on?

You're only in it for the money!



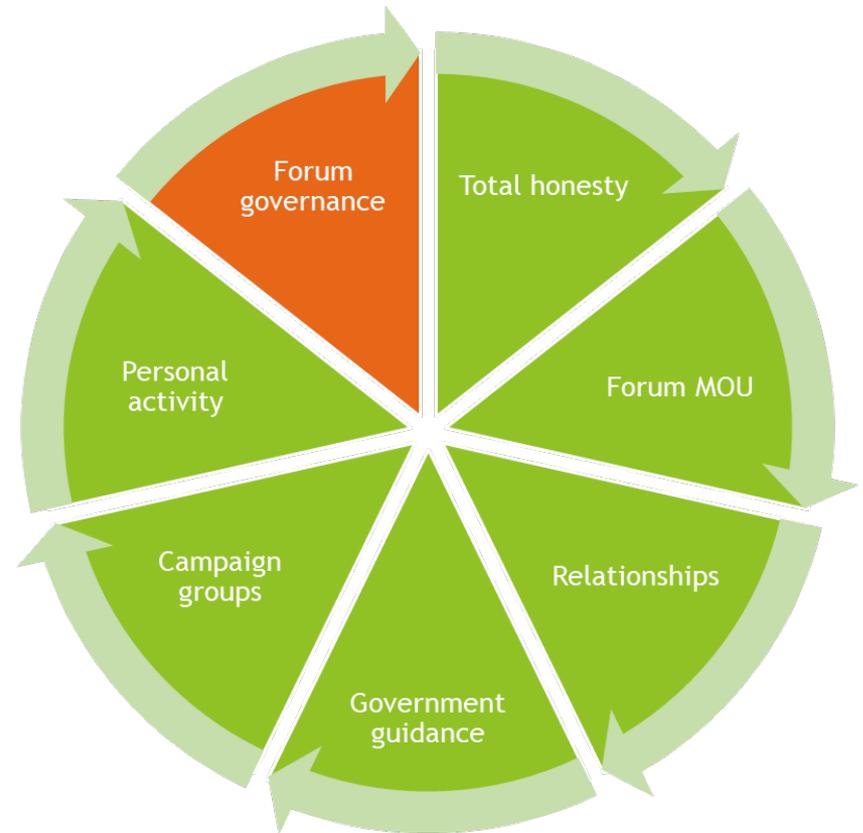
Personal activity

- ▶ There is nothing to stop any member of a PCF engaging in campaign activities as an individual
- ▶ Just be aware of perceptions - not everyone will understand the difference between personal and forum activity
- ▶ Review Forum's Code of Conduct and conflicts of interest policy



Forum governance

- ▶ There are no hard and fast rules
- ▶ You need to assess and manage each situation individually
- ▶ Make sure you stay true to your own forum's governance documentation and way of working
 - ▶ Constitution
 - ▶ Articles
 - ▶ Strategy
 - ▶ Values
 - ▶ Ethos





“We do this and other things, not because they are easy, but because they are hard”

John F. Kennedy 1962

<http://www.nnpkf.org.uk/useful-information/myth-busting/>





"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."

Margaret Mead



Thank you!

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Thank you for attending the webinar today.

A short questionnaire will launch at the end of the webinar.

Please take the time to complete this as it will help us to plan future online training events.

The recording of the webinar and presentation will be available on Contact's website in the next two weeks. Look out for news about this on our homepage and social media networks.

